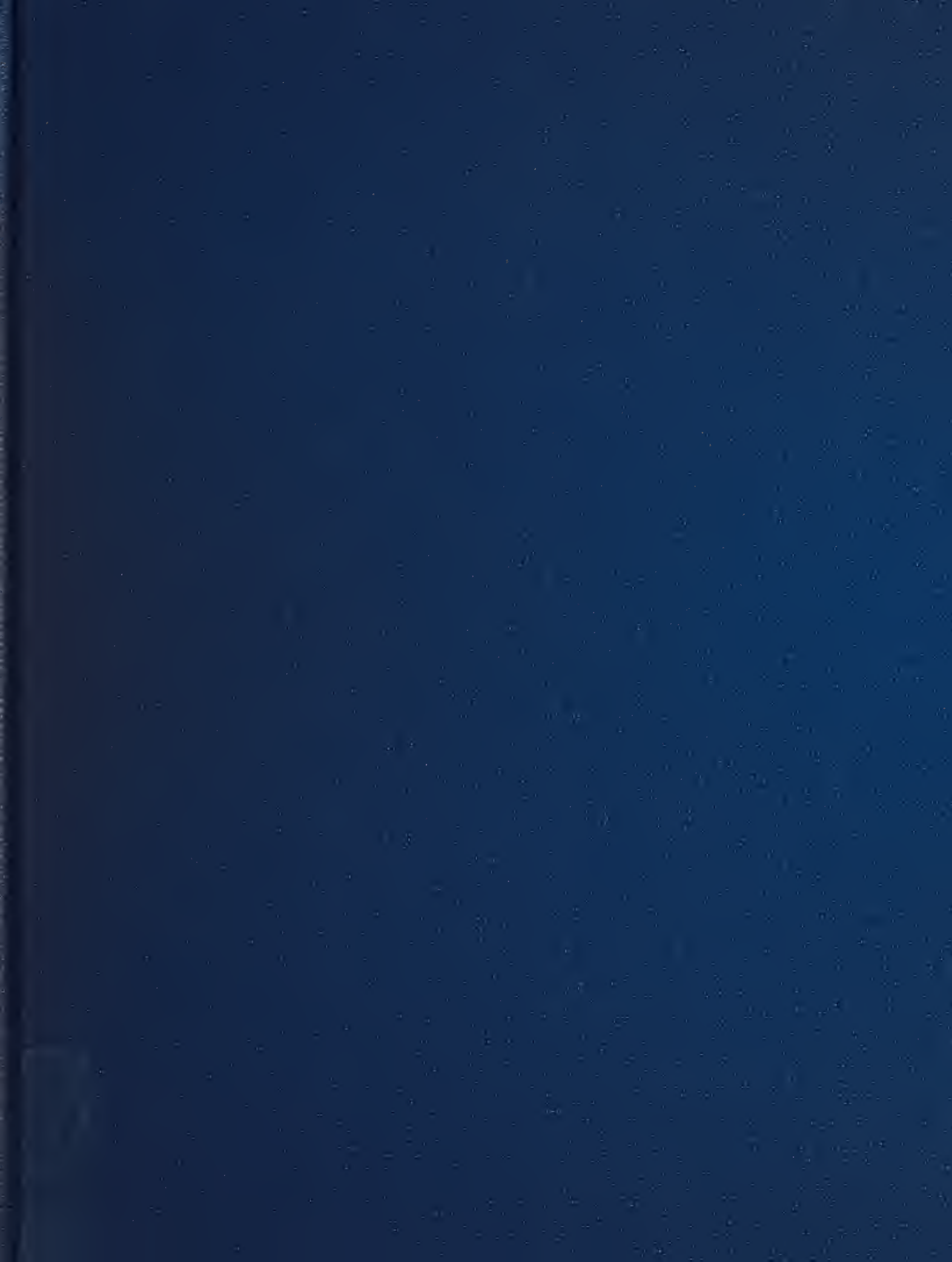




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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II

Carol Fewell Billings

ATTENDANT AND OBSERVER IN THE EARLY DAYS OF THE
PHYSICALLY DISABLED STUDENTS' PROGRAM AND THE
CENTER FOR INDEPENDENT LIVING, 1969-1977

Michael Fuss

ATTENDANT FOR COWELL RESIDENTS, ASSISTANT
DIRECTOR OF THE PHYSICALLY DISABLED STUDENTS'
PROGRAM, 1966-1972

Linda Perotti

AN EMPLOYEE PERSPECTIVE ON THE EARLY DAYS OF THE
COWELL RESIDENCE PROGRAM, PHYSICALLY DISABLED
STUDENTS' PROGRAM, AND THE CENTER FOR
INDEPENDENT LIVING

Interviews Conducted by
Kathy Cowan
and Sharon Bonney
1997-1998

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Carol Fewell Billings and Bill D'Argrie, Grass Valley family ranch.



Michael Fuss.



Linda Perotti, 1998.

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SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbscuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

Simi Linton, Ph.D., Co-Director
Disability Studies Project
Hunter College

New York, New York
April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C., was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

Regional Oral History Office
The Bancroft Library
University of California, Berkeley
September 1999

August 2000

Disability Rights and Independent Living Movement Oral History Series
The Formative Years in Berkeley, California

Single-interview volumes

Mary Lou Breslin, *Cofounder and Director of the Disability Rights Education and Defense Fund, Movement Strategist, 2000.*

Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis, 2000.*

Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000.*

Charles Grimes, *Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967-1990s, 2000.*

Deborah Kaplan, *National Policy Advocate and Leader of Disability Rights Organizations, 1976-1990s, 2000.*

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Joan Leon, *Administrator at Berkeley's Center for Independent Living and the California Department of Rehabilitation, Cofounder of the World Institute on Disability, 2000.*

Susan O'Hara, *Director of the UC Berkeley Disabled Students' Program, 1988-1992, Coordinator of the Residence Program, 1975-1988, and Community Historian, 2000.*

Corbett O'Toole, *Advocate for Disabled Women's Rights and Health Issues, Founder of Disabled Women's Alliance, 2000.*

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Susan Sygall, *Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues, 2000.*

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Judy Heumann, Deputy director of the Center for Independent Living, cofounder of the World Institute on Disability, assistant secretary of the U.S. Department of Education. (in process)

Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

Pat Wright, Director, Governmental Affairs Office of the Disability Rights Education and Defense Fund, strategist for the Americans with Disabilities Act. (in process)

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John "Jack" Rowan, *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982.*

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Anita Baldwin, *Deputy Director of the Center for Independent Living, Early 1980s: Observations of Blind Services and Staff Strike. (in process)*

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VIDEOTAPED INTERVIEWS:

Mary Lou Breslin, Kitty Cone, Neil Jacobson, Joanne Jauregui, Deborah Kaplan, Johnnie Lacy, Joan Leon, Susan O'Hara, Zona Roberts, Ken Stein, Herb Willsmore, Hale Zukas.

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University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II

Carol Fewell Billings

ATTENDANT AND OBSERVER IN THE EARLY DAYS OF THE PHYSICALLY DISABLED
STUDENTS' PROGRAM AND THE CENTER FOR INDEPENDENT LIVING, 1969-1977

An Interview Conducted by
Kathy Cowan
in 1998

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INTERVIEW HISTORY--Carol Fewell Billings

Carol Fewell Billings was interviewed for the Disability Rights and Independent Living Movement Oral History Series because of her involvement in the Cowell Hospital Residence Program, her work as an attendant, and her employment at the Physically Disabled Students' Program and at the Center for Independent Living. In addition, she had close friendships with the leaders of the movement, members of the community, and was married to Larry Langdon, a participant in the movement in the early days at Cowell Hospital.

Ms. Billings recalls her first days in Berkeley in 1969 and the troubled, but exciting, events on campus. She remembers the early days of the Physically Disabled Students' Program and was present when the Center for Independent Living was established. She speaks of her experiences working at both programs and talks about her memories of the directors, John Hessler and Ed Roberts.

Ms. Billings returned to Humboldt County in 1977. The interview took place at her home in McKinleyville, California, on July 23 and 24, 1998. She made few changes to her transcript, adding some names and dates, and some notes to clarify.

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Kathy Cowan
Interviewer/Editor

September 1999
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Carol Diane Fewell Billings

Date of birth 12/30/49 Birthplace Scotts, CA

Father's full name Benjamin Jay Fewell

Occupation retired teacher Birthplace Texas

Mother's full name Evelyn Joyce McFarland Fewell

Occupation retired teacher Birthplace Oklahoma

Your spouse _____

Occupation _____ Birthplace _____

Your children Caitlin Emma, Jacob Marcus, Carin Nova

Where did you grow up? Humboldt County, CA

Present community McKinleyville

Education single subject teaching credential, English BA, & credential Humboldt State University, Eureka, CA

Occupation(s) teacher

Areas of expertise high school, adult school, ^{high school diploma program at} alternative sites (homeless mission, jail)

Other interests or activities writing, gardening, environmental issues

Organizations in which you are active belong to 2 writing groups

INTERVIEW WITH CAROL FEWELL BILLINGS

I LIVING IN HUMBOLDT COUNTY AND BERKELEY

[Interview 1: July 23, 1998] ##¹

Meeting Larry Langdon in McKinleyville

Cowan: Interview with Carol Fewell Billings, July 23, 1998, tape 1, Side A. Carol, why don't we start with something about your background. Where were you born and raised?

Billings: Humboldt County.

Cowan: Humboldt County? Right here?

Billings: Yes. I lived here pretty much--with three years in Sacramento Valley and one year in Texas when I was very small, but other than that I lived here. I graduated from the high school just down the road half a mile and went to the school across the street. When I was nineteen I met Larry who lived down the street from me. We lived, actually, down Hayes Road which is a mile the other way.

Cowan: Is that right?

Billings: And he lived two doors down. I think I was a junior in high school when he came home from rehab. I had never met him before.

Cowan: This is Larry Langdon?

Billings: Yes. My friend who lived down on the corner knew him and knew his story. Actually, I guess we had lived down in Fieldbrook and just moved back to McKinleyville, so I didn't know his family, but Sherry knew him. She came up and she said, [in

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

whispered voice:] "The neighbor boy's back from rehab. You know, he had an accident and he's paralyzed and I want to take him out for a Coke, will you go with me?" Because she was scared to take him by herself. I went, "Oh, sure, yes," and so off we went to get a soda [laughs] and that was that.

Cowan: What year was that?

Billings: Gosh! That was either '67 or '68 because we were friends for a couple of years. He would come home for vacations from UC and you know, we were like buddies. I'd go down and we'd play cards or, you know, go out for a drive, or whatever.

Cowan: You'd go down to Berkeley or down to his house?

Billings: No, just down in McKinleyville when he was here home.

Cowan: How did Larry have his accident?

Billings: He was diving in a river. I think it was Mad River, actually, when he was eighteen. He had been sent away to a boarding school in Canada by his godfather who apparently recognized his intelligence--he came from a redneck logging family and was a brilliant child. He was sent to this prep school in Canada. And when he came home the summer after he graduated he was out in the river and dove in and hit bottom, which is I think what happens to a lot of people.

Cowan: He was at UC but you were still here?

Billings: Yes, I was in high school when we met. I was either a junior or a senior.

Cowan: What year was Larry in, do you recall?

Billings: He had just started, I think. He was either in his first or second year at that point. He was very new. In fact, at that time he was living at Cowell, I'm pretty sure--Cowell Memorial Hospital.

Cowan: I think he was one of the first.

Billings: Yes.

Cowan: Can you recall anything he said about the program to you?

Billings: He didn't really say anything about the program--

Cowan: I mean what was going on at Cowell, or how the university was working for him.

Billings: No, I can't. [laughs] I know he was very close with Jim Donald. And in fact, by the time I graduated from high school and we started becoming more seriously involved, he and Jim and Jim's wife Lily were living in an apartment on Haste Street, just above Shattuck. I did go down to visit him there-- probably the fall of '68.

I had a roommate at the YWCA where I lived and she had a brother at the school for the deaf--the old one, it was close by--and I said, well, I have a friend down there, and so we went down to Berkeley and wow, what an experience for this little hick. [laughs]

Cowan: Did you go down to visit or down to live?

Billings: Oh, to visit.

Marriage to Larry Langdon, 1969, in Berkeley

Billings: At that point things took a turn for the real serious between him and me and we started talking about getting married, which was just crazy, but you know, I was young. That was probably later in '68, close to the end of '68 because a few months later I packed up my stuff and got on Greyhound and off I went and got married a couple days later.

Cowan: In the fall of '68?

Billings: No, it was in April of '69.

Cowan: Where did you get married?

Billings: In the apartment [laughter] with Jim and Lily and their dog. This Presbyterian pastor came over and married us.

I remember the biggest thing was to try and figure out what I was going to wear. And we had this wonderful cake that was pretty much strawberries and whipped cream. [laughter]

Cowan: Any other people at the ceremony?

Billings: No. Just Jim and Lily and their dog. [laughter]

Cowan: What do you remember? What was Berkeley like then when you got there? What was the neighborhood like?

Billings: Well, I lived on the south side, so there were students. To me it was just unbelievable, you know, coming from here where it was so quiet and so rural and so conservative--to land--I'd thought I'd gone to heaven. [laughs] And the idea of an apartment--it was just magnificent to be in this apartment separate from my family. So you know, as far as Berkeley itself, it was being compared to my previous experience.

People's Park Incident and Troubled Times in Berkeley

Billings: One of the things that happened very soon after that was People's Park. That was an extreme incident.

Cowan: Do you want to say a little bit about what that was?

Billings: There was a piece of land up on Telegraph and maybe Bowditch, a little south of Dwight, owned by the university, and people began to use it as a park. At a certain point they began to organize and they started bringing in flowers. I remember the day they brought in rolls of lawn--of sod--and started putting lawn down. Of course this was a time when the people were much more important than the government--that's hopefully always true, [laughs] but anyway it was really a big thing then.

The university got really nervous because their piece of land was going away. So for a few weeks it was all music and laughter and flowers and people dancing in the park and probably other stuff, too, but then the university threw up a chain link fence around it and it was basically no trespassing. And the city went wild.

There were riots at this point that I'm remembering. The National Guard came in and we were an occupied city. It was the strangest feeling to walk down the street and every corner --well, the streets were lined with National Guard and it felt so oppressive. I had never imagined being in that kind of situation.

I remember [laughs] somebody, I can't remember who it was, but someone who was in a wheelchair was going down the street and was in some kind of trouble or something and a national guardsman helped him up and he said, "Pig!" to him and was telling us about it and we were all laughing.

Cowan: Were the Oakland police there as well?

Billings: Well, now, I had a little incident with the Oakland police right after I was married. There was a lot of rioting going on and I had a broken hand because I'd been in a car accident on one of my trips down to Berkeley before I got married. At that time there weren't many ramps. Sproul Plaza had this one place with a dip where wheelchairs could go up real easily and that's where they always went on and off campus. I had gone to class with Larry. My ex-roommate was down visiting--so there were two nineteen-year-old girls and this guy in a wheelchair and me with my arm in a cast, and we'd been on campus going to class and we were coming off campus.

There'd been rioting going on all day and the Blue Meanies (what we called them--the Oakland police) were lined up on Bancroft, facing Sproul, and there was a group of maybe fifteen or twenty demonstrators back a few hundred yards. So Larry and Lynn and I were be-boppin' along, going towards the ramp to get off campus and you know, I saw them there, but I felt like well, we're just leaving campus, so we're perfectly okay, and all of a sudden they just started throwing tear gas at us.

And [laughs] I was just totally, totally surprised. I remember standing there--it was only for a brief instant, but with my mouth at least minimally open going "What!"--just totally blown away and feeling extremely--I don't know if self-righteous is the word, but you know, how could they do this, you know? And then of course I turned around and ran.

I remember Larry scooping up a tear gas can and starting to throw it back at them before he wheeled around and buzzed off. So we ran off and yes, they were there.

Another time I was walking up to one of my jobs because I cooked--this was actually not at that time, this was another riot--and there were some police and some demonstrators, just kind of milling around. There wasn't anything really bad going on, but I was so freaked out that I could not go past them, so somebody had to walk me past. It was very strange. It was very frightening.

Cowan: There was lots and lots of turmoil in that whole period. After you were married, you went to work? You got a job or did you go to school?

Billings: I did go to school, but not right away. I started working in San Francisco at an insurance company.

Cowan: That was your first job?

Billings: If I can remember right that was my first job. It was the St. Paul Insurance Company. I worked there about three months and it was so boring--I would get my work done and then sit and try to look busy. I couldn't stand it and so they called me in and said I either had to start coming to work every day or quit and so I said, "Well, I think I quit." After that I started going to school I think in January 1970.

Cowan: At Cal?

Billings: At Cal, yes. I would go to school generally for a quarter and then drop out and work until I got some more money together.

Cowan: What was Larry doing?

Billings: He was still in school. He graduated in one of the first years we were married.

II COWELL HOSPITAL RESIDENCE PROGRAM AND THE PHYSICALLY DISABLED STUDENTS' PROGRAM

Work as Attendant at Cowell

Billings: And I also started working as an attendant. I can't even remember who I first started working for--probably Cathy [Caulfield], [laughs] or Judy Taylor. I worked for Judy Taylor and Cathy. They were my main people.

Cowan: Were they at Cowell when you were working for them?

Billings: No, Cathrine probably left Cowell soon after I got there. I remember Judy being there. I remember when she arrived and I remember she was injured in a car accident. And that was kind of a new thing.

I remember being at Cowell a lot, though. I don't remember why but I was up there a lot.

Cowan: What do you remember about it?

Billings: It was fun. [laughter] It was fun to go up hang out and meet new people. We'd play music or hang out.

Cowan: What did it look like up there? Were there posters on the wall? Was it painted or was it an hospital atmosphere?

Billings: It seemed pretty hospital-ish, except there were people buzzing around having a good time or studying. I think the rooms were probably fairly personalized, but I don't remember to tell you the truth.

Cowan: Do you remember any of the other attendants up there?

Billings: Well, Linda Perotti was Cathy's first attendant. In fact, it was such a thrill to get to work for Cathy because Linda was

her attendant. And Linda was like the goddess, you know. Well, to me. I really looked up to Linda Perotti, oh yes. She was someone to admire.

Cowan: What made you decide to try that, to be an attendant?

Billings: It was a job, and it was people I knew, and it was money, and I had worked here as a nurse's aid.

Cowan: Here?

Billings: Actually, now that I think of it, I worked in Berkeley as a nurse's aid, too, at a convalescent hospital. So I knew the stuff.

Cowan: What stuff?

Billings: The attendant kind of stuff--you know, bathing and getting people dressed and how to lift and all that kind of stuff. I'd done it.

Cowan: So you didn't need any further training on this?

Billings: Oh, I'm sure I did, yes, because there were things involved with active people that weren't involved--people in convalescent hospitals are fairly passive and it's basically keeping them clean and maybe moving them some. With active people you've got a lot of stuff that--just in terms of catheter care or what people want--just in terms of getting them dressed--people want to get dressed a certain way and so there was not the passivity that there was in that other kind of place.

Cowan: But they would pretty much be able to tell you what they wanted.

Billings: They knew exactly what they wanted! I mean, this was part of the deal. [laughs] So once I started doing that I really liked the flexibility. In a sense there wasn't flexibility because if you said you were going to be there, you had to be there. I felt real strongly about that.

In fact--this is kind of strange--one of the women that was an attendant who was part of the community killed herself and I was really pissed off at her because she did it with someone waiting for her the next morning. That was a very small part of my reaction, but I remember thinking, "She was supposed to show up to get somebody up in the morning, you know?" Of course she had bigger problems than that obviously.

Memories of Staff and Students

- Cowan: We were talking about Cowell, still, so if we could stay with that for a little bit--
- Billings: Well, another person that was real important at Cowell was Edna Brean, of course.
- Cowan: She was a nurse?
- Billings: She was a nurse, yes, and I don't know if she was the director, or what, but she had a position of power there. And there was another woman whose name I can't remember.
- Cowan: Was it Eleanor Smith?
- Billings: Eleanor, yes, who I assume was the original nurse.
- Cowan: Yes.
- Billings: And then Edna came on. I knew Eleanor very slightly. But they were in a funny position I think now, because they were in a powerful position. They were in a position of knowledge, and at the same time these radical people were coming up saying, "We're going to decide. We want to have control over our own lives." And so it must have been a funny position to be in, just looking back.
- Cowan: Do you recall them expressing that in any way?
- Billings: I don't remember Edna expressing that. I remember there being tension later, probably as the organization was becoming more self-actualizing, if I can use that term. I don't remember anything specific. I remember feeling like Edna's not doing what she's used to doing and people aren't letting her have as much power as she used to have. I have nothing to tell you that happened or anything, I just have that memory of that.
- Cowan: Do you remember John Hessler or Ed Roberts there? Were they there when you visited?
- Billings: I believe Ed had gone to Palo Alto by then, or maybe to Washington, or wherever he had gone. I don't remember the first time I met Ed, but he was always a presence even before I met him. He was a presence because he was like the guy who started it.

John may have been there then, I don't remember. But I remember John, of course. John and I were very close. I lived with him for a while; he rented me his living room [laughs]--me and my dog--and we would fight horribly. I mean, he was a very strong personality.

Cowan: But you don't remember him at Cowell in these very beginning years?

Billings: No, I don't. Cowell is very hard because I was so wrapped up in my new husband at that point and all our problems. And then being newly married and everything, I was sort of self-absorbed. [laughter]

Cowan: Do you recall any little details, like how much you got paid as an attendant?

Billings: Oh, gosh! Boy, I wish I did. You know, I used to write stuff like that down, and I have no idea where it would be.

Cowan: It just would be interesting.

Billings: I remember what I got paid at the convalescent hospital in Berkeley and that was \$1.65 an hour--\$1.70 when I cooked. So I can't imagine that it was too much more than that when I began. I may have gotten up to \$6 an hour, but that may be mixed up with my house-cleaning jobs, too, so I don't know. Four dollars an hour rings a bell for some reason, at some point in my career. [laughter]

Cowan: So you were married to Larry, he was going to school, you were working as an attendant and going to school yourself.

Billings: Right.

Cowan: Was there a community evolving here of attendants or people with disabilities?

Billings: Well, yes, that's what we were in. It was like a subculture of Berkeley. And it was wonderful because--I've thought a lot about how much trouble I could have gotten into [laughs] at that time in that place. I know a lot of people who you know went down to the Bay Area and whatever and got involved in drugs or crime or, you know, different kinds of things as a way of working against the system at that time. I feel like I was in the best of all possible worlds because I got to have that experience of being rebellious in an extremely productive and positive way and learned so much about so much. Part of it was having that community. And Larry was one of the people who was

at the beginning very important although his drinking problems, I think, really lessened his impact.

The Rolling Quads and the Origins of PDSP

Cowan: This was the beginning of PDSP that you're talking about?

Billings: Just the whole movement, including PDSP, yes.

Cowan: Do you recall at all how that got started? Do you recall at Cowell--I've read about the Rolling Quads.

Billings: Oh, God, I forgot about the Rolling Quads. Oh my God! [laughter] Not as far as bureaucracy and so forth, I don't remember a whole lot about it, but I remember that there were certain things that people needed and they were determined to get them. And there were some extremely intelligent and powerful people in that place at that time.

Cowan: Who were they?

Billings: Well, Ed, Larry, Jim, Herb [Willsmore], and Judy to a certain extent.

Cowan: Were they the Rolling Quads?

Billings: I don't remember because I think the Rolling Quads, if they were still going on--rolling along--when I was there they were single people probably. [laughs] It's hard to separate some things out. And John and Don Lorence, together they were practically unstoppable, it seemed like at the time. I was in awe of them.

Cowan: They were the core group whenever that developed?

Billings: It seemed like that to me, yes.

Cowan: And what did they develop?

Billings: Well, in terms of the university they got a place and money to start the disabled students' program--PDSP. Is it still called PDSP?

Cowan: It's called DSP now. Do you recall how they got their original funding?

- Billings: No, I don't, but I think it was federal, because I remember hearing a lot about HEW. I started working at PDSP, probably after Larry and I split up. I can't quite remember. I did a lot of typing of grants and so forth. And HEW was an important place, I think for money and also for sending statistics--that sometimes we just kind of made up. [laughs] I mean, we didn't really make them up, but we kind of extrapolated them.
- Cowan: Were you still doing attendant work when you went to work for PDSP?
- Billings: Yes, I did attendant work off and on until I left Berkeley.
- Cowan: Can you remember where you were living when you went to work for PDSP?
- Billings: If Larry and I had split up which we possibly had--the first place I lived was on Channing and Ellsworth, but I'm not quite sure. I only lived there for month. Couldn't stand living by myself and then I moved in with John.
- Cowan: Hessler.
- Billings: Yes. And then I moved to another place by myself and that was awful. And then I kind of stayed with Judy for a while. Oh God, this is so confusing, but eventually I moved in with Susan [O'Hara], and I lived there for I think maybe a year, I'm not sure. We had lots of fun. [laughs]
- Cowan: Were you working at PDSP when you were living with Susan?
- Billings: You know, I worked back and forth so much between PDSP and CIL that it's hard to know when I worked where.
- Cowan: Well, which one started first?
- Billings: PDSP. In fact, I remember CIL beginning in the closet at PDSP. Phil Draper and probably Ed--I can't remember who else--they had a door in this closet for a desk top that was wheelchair high so they could fit under it. It feels like that was where their office started, was in this closet. [laughs]
- Cowan: Was that at the PDSP office on Channing?
- Billings: On Durant. The first physical office I remember was on Durant.

People, Jobs, and Services at PDSP

Cowan: What do you remember about PDSP?

Billings: I remember thinking that this is so great to work here because it was almost like not work. I mean, it was work: there were things to be typed, there were phones to answer, and people to call and so forth. And during grant-writing time it was always crazy and long hours and cutting and pasting and typing on my old Selectric. [laughter] I thought I was in heaven! An electric typewriter!

And then there was the communal atmosphere which was wonderful because the walkies would cook and the crips would put in money. That's what we had--we were walkies, and they were crips. We would take turns cooking--each person had a day.

Cowan: Who was there?

Billings: Well, I was there, and I know Chuck Grimes was there because he would make an Indian dish with curry and fruit and lamb and, oh, it was really good. And I think Andy--

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Billings: There were two Andy's. They both did wheelchair repair. Maybe it was Andy Cayting, I don't know. I can't remember, but he was there, and Zona was there, of course; Mike Fuss. I remember Mike because we always were trying to find foods that he could eat because he had a problem with allergies where he couldn't eat wheat or a lot of stuff. And Zona used to try to make him a birthday cake with brown rice flour. [laughs]

Lunch was the pivotal point of the day in a way, a lot of times. We all gathered. We ate together and someone had cooked the food and it really added to the feeling of community that we had. And I really loved that.

Cowan: What was everybody's job? What did Zona do?

Billings: What did Zona do? [laughs] Zona, what did you do? [laughter] Zona was like the queen, that was her job. You know, I'm not sure. She would come in and she would--she would do stuff with Ed, she would feed Hale [Zukas] if he needed to be fed--I'm not even sure if she even worked there at that time; she was just there. She would do the shopping for the office, she would find the day old bread and stuff, but I don't remember her

actual job or if she had one or if she was just there for some reason.

John was the director. Don was the assistant director--

Cowan: Don Lorence?

Billings: Yes, at a particular time. I mean, things changed of course.

Cowan: Right.

Billings: Chuck and Andy were wheelchair repair.

Cowan: Did they only do wheelchair repair? Did everybody only do one job or did everybody do everything?

Billings: Well, wheelchair repair--I couldn't do that. I mean, you know, that's pretty much what they did and transportation. But as far as the director and the assistant director stuff went, that was pretty much theirs too. I did clerical work and I also learned how to do supportive services: getting attendants and doing some advocacy and you know, things like that.

Cowan: How did you find attendants?

Billings: We must have advertised. And Zona was really active in the CO thing--the Conscientious Objectors--so she would get people. In fact, she had people living in her house who were COs and it was kind of like this conduit to the disabled community because they needed service work and here was the perfect work. And word of mouth. God, I don't even remember how we did it, [laughs] but it was done!

Cowan: How about helping people to find housing, did you do that?

Billings: We did it to a certain extent. Actually, for PDSP a lot of what we did, or a lot of what I remember doing as I became more competent, was working with students who were coming into the university. You know, it's different. I sort of get mixed up between CIL and PDSP because they would be completely different. At the university, you've got people coming into Cowell or into the dorms--that's the first place you would look for housing. And we must have had listings or other ways to find it, too, or just to help them if they were looking for a house--help them to get a ramp put in or to modify the place in some way or other--because there were people out there who were willing to do that kind of thing; maybe they weren't attendants, or maybe they were attendants, but they also would build a ramp, or come in and fix shelves or whatever it was.

There were just so many people who were not into working nine to five but who needed jobs.

Cowan: So the attendant pool was always--

Billings: I don't remember ever having a problem with attendant pool.

Cowan: Did everybody get served? Did you feel that PDSP served all the students? Were all of their needs met? Do you have a recollection or opinion about that?

Billings: I don't have any remembrance of feeling like someone was not being served--at least basic needs.

Cowan: Which were?

Billings: Attendant care if they were physically disabled, mobility; we also worked with the university in terms of getting registered for classes and so forth. That was kind of the easiest thing in a way. Helping them get their benefits was another one.

Cowan: Where would they get benefits from?

Billings: Welfare.

Cowan: The state?

Billings: I don't remember. Attendant care money from the state--I don't think SSI existed then, but whatever monies were available. It was a big issue. [laughs]

Cowan: But you remember you helped to get it.

Billings: I have some stuff written down: mobility, supportive services, advocacy--it was independent living kinds of stuff.

Cowan: This program existed to serve the students--PDSP?

Billings: Yes, yes. So we had to sneak the other people services. [laughs]

Cowan: And how much of that happened before CIL was born? Did you help anybody who came in or did you say, "Sorry, you're not a student, we can't help you?"

Billings: I remember having to refer people elsewhere, but I don't remember ever saying, sorry, the door is closed; although I don't know if that happened, I wasn't there all the time. I never worked full time I don't think. But there was not a

sense of this is where we draw the line right here; it just wasn't that kind of place. I can't imagine just saying, "We serve students only," although at a certain point they may have had to start doing that.

Transportation Issues and Ramps

Cowan: When you say that Chuck and Andy worked on wheelchair repair and transportation, what do you mean by transportation?

Billings: There were university vans that we were able to use. There was a boat--it was actually a station wagon but we called it a boat. Zona was always driving the boat--a big old yellow station wagon. So if someone needed to be taken somewhere, they would have to make an appointment, or if there was an emergency, Chuck or Andy would drive them or sometimes Zona would drive them.

So there were vans that had wells--they had a lift, of course, and then a well--slight, at least to anchor people. Eventually I think John [Hessler] was driving one of the vans or he had his own van. I can't remember.

Cowan: So they took students wherever they needed to go?

Billings: Right. If you're on south campus and you go to the university there aren't that many places you need to go, but you know, if you need to go to the doctor in Oakland or something or catch a plane to somewhere, then we'd drive people.

Cowan: You mentioned Hale Zukas. What was Hale's job there?

Billings: Hale dealt with the city government and BART [Bay Area Rapid Transit]. He did a lot of stuff with BART in terms of public transportation. When BART was being developed and built he was there to test things out. I remember him going through and telling them, "Well, this is wrong, and this has to be done."

Cowan: So he dealt with transportation on a governmental or liaison level?

Billings: He dealt with things on a bigger level than just the ramps. The first thing that was done was the city was ramped. And that was a big deal. Eric [Dibner] probably told you he used to go around with a bucket of asphalt and a shovel. [laughter]

Well, finally they got the idea and redid Telegraph Avenue completely. And I don't know if they did it just for the ramping but when they did it, they put in the cobblestone part and ramps on every corner. I believe people from our office were the ones to consult with them on the proper grading and how to do it so you're not being thrown into the street and so forth. At the time it was this mecca for anyone who had mobility issues.

Cowan: Do you recall any dealings with the university? Did anybody from the university act as liaison?

Billings: I recall us trying to stay as far away from the university as possible. [laughter] I don't know if that was just me or if that was really true, but we were an entity unto ourselves in a way and it seems like we preferred that because there's so much bureaucracy in a school, especially one like UC. And we were little rabble rousers, in a way.

Cowan: But a part of UC. That's who your employer was.

Billings: We were part of UC, yes.

Cowan: What about Larry Langdon? Did he have any role?

Billings: Larry didn't have much of a role that I remember. He went to meetings. I remember him going to meetings and so forth in the early days, but he was pretty much concentrating on school and then graduate school because he went to San Francisco State and to do rehab counseling. And this is embarrassing but I don't remember what he did with PDSP. And of course by CIL I think he was pretty far gone. [pause]

Larry Langdon's Death, 1977

Cowan: What do you mean by pretty far gone?

Billings: Well, the year he graduated from graduate school we had already split up and he was a very heavy drinker. When he graduated I think he was at loose ends and he started drinking. I remember him coming up to PDSP and he was drunk in the middle of the day and it was like he had been drinking for a week or something. From what I can gather he went out that night with a bunch of the young kids who were more into drugs and on top of this week-long binge was taking drugs. I don't know if he went unconscious or went into--whatever, he had a severe enough

episode that an ambulance was called. He was taken to the hospital. He was in a coma for a long time; when he came out, he had lost his memory. He didn't know me, he didn't know anybody. It was blank.

Cowan: That severe?

Billings: Yes. It was very severe. Slowly it started coming back. I would go visit him just because I was so concerned and for a long time he didn't know who I was.

Cowan: Go visit him where?

Billings: At Herrick Hospital.

Cowan: Then what happened?

Billings: Then he went home. He came up to Humboldt County for a while and then he went to--it was told to me--it was like a halfway house, kind of between independent living and non-independent living down in San Jose. And there was a heat wave and he died.

The only thing that I was ever able to figure out was that when someone has a spinal cord injury, there are changes in the autonomic nervous system and part of that is temperature control. In fact, I think it was either in 1969 or 1970 Jim and Lily and Larry and I went to Calaveras County for the frog jump [frog jumping contest] and this is where I started to hear about this because they weren't able to cool themselves by sweating and Lily and I had to drape ice-cold washcloths on them to keep them cool.

Cowan: So he died.

Billings: He died. And I don't know if it was heat stroke or what. He was probably thirty.

Cowan: That would have been about what year?

Billings: Well, Caitlin was a baby so it was probably 1977 because I had come up here. It was 1977, I'm pretty sure.

Cowan: So Larry didn't ever have a role at PDSP or CIL?

Billings: He never worked there. He was part of some of the planning and so forth in the beginning of PDSP, but I think, well, he was really into the end of school and getting into graduate school and so forth. He was a central figure in the community--

Cowan: Yes, I read his name all the time.

Billings: He may have done things that I wasn't aware of, too, because like I said, I was pretty self-absorbed sometimes.

Cowan: Well, you were young.

Billings: I was young and I was also dealing with having an alcoholic abusive husband which was extremely difficult.

Cowan: You were divorced before he went off to graduate school?

Billings: We were divorced his first year.

Cowan: His first year in graduate school.

Billings: Yes.

More Memories of PDSP

Cowan: Well, back to PDSP then, you were working there. Anybody else you can remember being there--Hale, Ed, John, Zona?

Billings: Oh, yes, Dennis.

Cowan: Dennis.

Billings: Have you seen Dennis?

Cowan: No. Dennis Fantin?

Billings: Oh, gosh, I'd love to see Dennis--Dennis Fantin and Bob [Metts], his sidekick. Dennis and Bob would go white water rafting. Dennis was like Mr. Muscle Man--beautiful guy--but he couldn't see. I think Bob had polio so one leg and arm were affected but he could see. So Bob would call out where they were going, and Dennis would row. I never was there with them, of course, but they would tell these stories and they were so funny. Bob was the funniest guy in the world and Dennis was kind of the straight man, but what a sweet guy.

Cowan: What was Dennis' job?

Billings: Blind services. He was one of the people at PDSP. There was another guy there, whose name I can't remember. I think those were the only two I remember at blind services.

Cowan: So there were blind services and physically disabled services?

Billings: Well, the blind came afterwards. It started with the physically disabled and then blind got added and then deaf got added later. So it came bit by bit by bit--different kinds of disabilities and so forth.

There was some tension between the different groups. Yes, it's like, "Well, the physically disabled are getting all--are trying to take all the power," or, "You know, the deaf people want in and are they going to take--" And I don't know if it was just PDSP. I just mean in the community as a whole there was some tension around that. There was in-fighting and jealousy between different groups over who was getting more--money, power, recognition.

There would be tensions just like crazy. I remember before this demonstration--and I have pictures of it--there was infighting going on like you wouldn't believe. And Reagan saved us in a way because when he vetoed attendant care monies, everybody rallied together. It was like now we have a common enemy. It was a very human bunch of people, that's all.

Cowan: And the demonstration that you're mentioning, just for the record, was--

Billings: I believe it was held in San Francisco at a federal--

Cowan: Was this the veto demonstration that you're speaking of?

Billings: Yes.

Cowan: So when Reagan vetoed attendant care you had a demonstration about that?

Billings: Right, right. Yes.

Cowan: And it was in San Francisco, you are saying.

Billings: Yes.

Cowan: There was the big 504 demonstration in San Francisco as well.

Billings: When was that?

Cowan: Well, that was 1977.

Billings: Oh, no, I was gone by then. I moved back up here in very early '77.

Cowan: How long exactly were you in Berkeley?

Billings: Eight years. I arrived in April of '69 and I left in the early spring of '77 with my new baby.

III THE CENTER FOR INDEPENDENT LIVING

Moving to CIL from PDSP

- Cowan: You did attendant care, you began to work at PDSP and then CIL?
- Billings: Right. I started working at CIL when they had moved from the closet up to Haste and College. I believe it was their first apartment.
- Cowan: Before we get to where they moved, do you recall discussions about the need for it?
- Billings: Oh, yes. There was definitely a need for it, partly because PDSP in the community was doing such a good job of serving the disabled community. At least that was our feeling--that here was a place where people could come, they could live independently, they could be mobile, there would be people to accept them, they could be visible; and so more people would come in and they weren't students.
- Cowan: Do you recall who had those discussions about how to expand services?
- Billings: No. [laughter] I told someone the other day if I'd known there was going to be a quiz I would have paid attention.
- Cowan: But people began to be aware that there was a need to expand these services so they started in a closet on the Durant location.
- Billings: Right.
- Cowan: And Ed and John--

Billings: And Phil [Draper] and Hale were probably part of that. John was more PDSP, but of course he was involved. I mean, everybody was involved.

Thoughts on John Hessler and Ed Roberts

Cowan: What did you think of John as the director of PDSP?

Billings: John and I, it was almost like we were brother and sister--we had this love-hate relationship I think because he could be so arrogant and so powerful, and yet he could be so sweet, you know? He did a lot for me just in terms of having that kind of job. Being given responsibilities, for me, was really quite a wonderful thing. And he depended on me a lot. I wasn't his secretary or anything, but I was sort of the do everything girl. He could just piss me off sometimes because he could be so autocratic. What he said went, which is how I ended up working for CIL. [laughs]

Cowan: Is that right?

Billings: Jumped ship! [laughing] Yes, that's right.

Cowan: Did he have that effect on a lot of people?

Billings: Well, probably. I mean, I don't remember sitting around griping about John, but--yes, I think Cathy and I did a couple of times. That wasn't a work situation, that was in, I think, a social situation.

He could be a lot of fun, but he could be a real pain in the butt.

Cowan: But in a work situation his management style was--

Billings: Fairly autocratic, but he was very powerful at the same time. You know, I think he did a good job. At the time I really had no way of knowing except that things seemed to go smoothly and when there was an upset he would take control and take care of it. That was my view of it. I wasn't close enough to all the ins and outs and stuff to really know.

Cowan: So CIL was developing in the closet. [laughter]

Billings: They were soon to come out of the closet.

Cowan: And did there seem to be a natural movement of people? Ed would move to CIL--he would be the one to get that off the ground?

Billings: He did.

Cowan: It was Ed, mostly?

Billings: Well, Ed was a very, very powerful person in a much quieter way than John. John didn't shout really but I would characterize him as more loud. And Ed was very quiet but extremely powerful and extremely intelligent and able to move things that I don't know if anybody else would have been able to. But I think that--it's almost as if Phil were his intern or something, or the other people around--it was kind of like by working with him, they learned how to do things. And that's just my characterization. Somebody else might see it differently. I mean, Ed wasn't perfect, either. I mean, some people called him Fast Eddie, you know. It was like he was slick--he can get it through, you know--but in a way that's--

Cowan: By get it through you mean an idea he could get implemented.

Billings: Right, yes.

Cowan: With the university?

Billings: Well, no, not with the university, with whoever the powers that we were working with to get CIL off the ground. Maybe integrity wasn't always the top thing on his list, but getting the job done was. And maybe you couldn't always trust him because the first thing on his agenda was not maybe the people around him but getting things done or getting his baby born or whatever. I never inquired into that name that people would call him, but just sort of wondered.

Cowan: [laughs] Did you notice over this time that you were there, still at PDSP, that things were changing in the community in terms of discrimination against people with disabilities?

Billings: Well, when I first got there I was married to a disabled man and there was a lot of discussion, of course, within the community about personal relationships and how you deal with the different problems. And one of the problems was the way people would look at you and view you as a couple or as a person. And I think as more people became visible as independent human beings or powerful human beings or human beings with purpose or whatever--things sort of organically

started to change. Just by being around it, you can't but see things differently.

And then as PDSP and CIL became more of a force in the community, always with the idea that the leaders were the physically disabled and blind and deaf themselves, that was another way of changing people's views. And the other thing was keeping in mind that there are these people that need certain things so that whenever new streets were built, ramps were put in. It seems like a really small thing, but having that in the consciousness in the community was pretty important.

Cowan: Do you have any recollections of specific things that happened that made you think, "It was this way, and now it's changed?"

Billings: No. [laughs]

Cowan: No, you just could tell it was.

Billings: Yes, just the way when you go down the street with someone and people don't stop and gawk.

Cowan: Then, moving on to CIL, the core group moved out of Durant to Haste--

Billings: I think it was Haste and College, just below College, on Haste.

Cowan: What was that, was it an office?

Billings: It was in an apartment building. It was a two or three bedroom apartment in one of those three-story student buildings. Bill McGregor was there; he and I were together at that time. He was like the money man.

Cowan: The financial officer?

Billings: Something. Yes, I think he ended up being a CEO or something [laughs] but at the time he was just the bookkeeper. [laughs]

I got mad at John for something and I went up to CIL and with the purpose of asking Ed for a job and I went in and he had just come out of the cold into the office--and it was cold; it must have been winter or early spring or something--and I said, [in crying voice] "Ed, I have to talk to you."

Some Reflections on PDSP

[Interview 2: July 24, 1998] ##

Cowan: Carol, we were just finishing up with PDSP and your move to CIL yesterday, but I have a few questions still on PDSP that I wanted to ask you about. Do you remember thinking there were any negatives to the program?

Billings: I think the negatives that I remember were just personality conflicts. There was one episode, we had a couple of people who came in from what I would call outside the community and it was really hard working with them. I'm not sure whatever happened--I don't think they lasted. In those early days it was so--I don't want to say incestuous, that's such a bad word but [laughter] we were all so intertwined in each other that it was very difficult having someone from the outside come in.

Cowan: Do you recall who they were?

Billings: I don't remember the names, no.

Cowan: Or even from where?

Billings: No.

Cowan: Not from the university?

Billings: It was probably from the university. I'm just saying that because I worked at the university here and I know how things go with putting people in places.

Cowan: Do you think the problems occurred because they didn't want the decisions made by PDSP, by John, that they wanted to make decisions, or do you recall just the tension?

Billings: Well, the people who came in to work were lower level people, they weren't anyone who would be making decisions. I think possibly it was a matter of, first of all, not being immersed in the disabled community and standing out like a sore thumb just because of that and, second of all, being forced upon us. I don't know. I just remember that.

Cowan: Was John the main decision-maker? Was that ever shared with other people, or was he pretty much the person who decided?

Billings: I really don't know that. To me, he was so powerful--he had a powerful personality and I was easily intimidated, so what actually went on I don't know.

Cowan: Were John and Ed both there before Ed went off for CIL?

Billings: It was mostly John.

Cowan: Do you remember the actual physical setup at PDSP?

Billings: Oh, yes.

Cowan: Well, let's hear about that. [laughs]

Billings: Vaguely, of course.

Cowan: Yes.

Billings: You came in the back way, because there was a ramp there.

Cowan: This was above Top Dog, right?

Billings: Was it?

Cowan: I think so.

Billings: Yes, it was! Oh, gosh, I'd love to have a Top Dog with sauerkraut. [laughter] I forgot about those. You came up the ramp and went into this little small receiving office and then into a large common area which I think of as the lunch room [laughs] because that's where we always ate, but I think other things went on there, too. And then there was a little hallway into the kitchen, I believe, which was a very important room, and then into one of the main offices. If you went through the doorway, to the right, the wall on the right was the walk-in closet where CIL started, I believe. There was a desk against the wall perpendicular to the door and one across from the door and then there were probably other ones, too. And then you went to the right out a door and then into John's office, I believe.

Cowan: Where did you sit?

Billings: I probably sat a lot of places, but in that main last office before John's. And probably in the initial one--I don't know if there was an initial office or not, it just seems that way.

Cowan: What were the telephones like? Was there a phone in every office?

Billings: I'm sure there was at least one. I did a lot of telephone work. I think there were like three lines or something; it was very simple because when I went to CIL, of course we had this huge phone system--later, not initially. Yes, I was on the phone a lot. Don Lorence, I believe, lived across the hall in that building.

Cowan: Lived?

Billings: Yes, had an apartment there.

Cowan: Did things spill over?

Billings: I'm sure they did. [laughter] I remember having beer one day. It was after work, of course.

Cowan: Well, what was the social life like there? Did you have parties after work, parties on the weekends?

Billings: I remember a party at John's [laughs] where they played this song called "Don't Stop the Music" over and over and over. It was a country western song. People drank like crazy. There was a lot of marijuana. Ed always had the best dope in the world. People would have parties, they'd go places together, we'd hang out together, you know.

Cowan: Were there parties actually at the DSP office?

Billings: Not wild parties [laughs] that I was invited to, anyway, or that I know about. There were birthday parties, things like that.

Cowan: So social life was really integrated with the office?

Billings: Oh, for me, yes. Oh, yes. It was just one big party in a way, even though we were working. It was effortless in a sense. I'm sure there were times when we all wanted to kill each other and stuff, but--

Cowan: So, no really big problems that you can think of in terms of how PDSP served the community.

Billings: I can't think of any. Maybe I will in the middle of the night.

Beginning to Work at CIL

Cowan: Well, when we stopped last time, you had just gone to CIL when it was still in Ed's apartment and said to Ed, "I need a job."

Billings: [laughter] No, I didn't say, "I need a job," I said, [crying voice] "Ed, can I have a job?"

Well, Ed had just come in from the outside. He was cold. His driving hand, his one hand that was mobile which he used to steer his chair, was freezing and so he said, "Well, warm my hand up." So I took his hand and I'm warming his hand up, you know, rubbing his hand, and you know, warming it up and whining about what a jerk John was [laughs] and how I needed to come over to CIL for a while. And he said, "Okay, fine," you know, "no problem."

Cowan: "Just start."

Billings: "Just start." And I went, "Oh, thank you." [laughter] Because it was intense. I mean, it wasn't John. Working with John could be intense, but so could the whole experience no matter who I was working with. Sometimes a change relieved that intensity, if only temporarily.

Cowan: Was that how you were hired at PDSP, too, not a formal process, just you found yourself working there? [laughter]

Billings: I don't remember to tell you the truth, but probably. I may have had to fill out an application or something. I probably did for the university.

Cowan: Well, what was the setup like for CIL while it was still in the apartment--how many rooms?

Billings: There was a living room, and I believe there were two bedrooms. We weren't there very long. In fact, I have little memory of that place, other than getting a job. [laughs] I think they were only there a month or two.

Cowan: So you don't recall students coming in for services?

Billings: Well, students were not applying for services.

Cowan: I mean, not students, but people with disabilities.

Billings: No. I think it may have still been in the more bureaucratic planning stage at that point. They were doing services but

that wasn't the main focus. It was more about getting funding and getting stuff going.

Cowan: When CIL did move, where did they move to and did you move with them?

Billings: I moved with them. We moved to University Avenue. I don't remember the address but it was above something--it was above a bookstore or a restaurant or something.

Cowan: People got in through the elevator?

Billings: Yes.

Cowan: And what was the setup like there?

Billings: It was bigger, it was much bigger. I can't remember the setup exactly, but it really had enlarged by then. I remember Don Galloway was the blind services director. He and I did not get along--I don't know why. After a while we did, but at first we didn't. I remember him because we didn't get along. [laughs] Mary Lester took my place when I left and either went back to school or back to PDSP. Lynn must have been there, Lynn Kidder, because she and Mary were great friends.

Cowan: What were you thinking at the time? Do you recall how you were feeling?

Billings: No. [laughs]

Cowan: Were you thinking this was just another job?

Billings: Well, no, it wasn't another job; it was just what was there, and what it should be. It was exciting to be working in something on the cutting edge, but you have to remember I was always really lower level. I was very much support staff.

Cowan: Right, but you did think cutting edge.

Billings: I was very proud of what we were doing and my part in it.

Cowan: Yes, so you were aware that this was a movement?

Billings: Oh, sure, but that was just part of the whole thing; it wasn't like I thought that out separately. It was like the social life was integrated, the movement was integrated, everything was integrated as far as I was concerned.

Cowan: And the community was going to change or things were going to change?

Billings: Oh, things were changing. Yes.

Cowan: Well, what was your job there?

Billings: Lord knows. [laughter] It was probably clerical still. In fact, I'm almost positive it was. I might have been assisting somebody, I don't know, but that was pretty much my job for a long time until we moved to the Telegraph Avenue part.

Cowan: So you were there pretty continuously?

Billings: Well, no, I left CIL on University Avenue because Mary took my place. And then I don't know what I did. And then I went back, I can't remember when, but I started out at the front desk as receptionist. I loved being receptionist: I loved putting the mail in everybody's boxes, I loved answering the phone and referring people.

Cowan: This was on Telegraph?

Billings: Yes, and then I did some stuff--I was actually Jeff Moyer's assistant for a while in blind services.

Working as Assistant to Judy Heumann

Billings: I asked to be transferred from there and Judy Heumann came on. She and I had been friends and I became her assistant and that's when things got really interesting because I would accompany her back to Washington, D.C. as an attendant/assistant/whatever. I got to go to subcommittee meetings and rub elbows and sit in the corner and be inconspicuous, but I just really revelled in the glory of it all. [laughs]

Cowan: That must have been really fun.

Billings: It was, yes!

Cowan: Can you remember the specific purpose of any of those trips?

Billings: Gosh, I wish I could remember the purpose. I was so starstruck by the committee members, I didn't pay attention at the time. And what I knew then has become fuzzy with age. But Judy Heumann might remember what this was about. I remember the

committee meeting--the subcommittee meeting--because Jacob Javits was there, Teddy Kennedy was there--I was this far from him--and it started with a W--he was in the Watergate hearings --I can't remember his name, but there were people who I'd seen on TV. And you know, it was just so exciting. Who cares what we're there for, you know, I was just going, "Wow."

She was giving testimony for something to do with something--I don't remember. But Judy was--Judy was fascinating in a sense because she was so up on how to deal politically and she'd worked for a senator there before she came to Berkeley and she knew Washington, D.C. like I knew south side campus. She was difficult to work for in a sense.

Cowan: In what sense?

Billings: She was very high-energy. She assumed everyone was going to have the same energy level and the same commitment to work twenty-seven hours a day as she did.

She never kept appointments--I have to tell you. I made lunch appointments with her many times, knowing she'd cancel and she did.

She had a phone in every room in her apartment, including the bathroom. And this was before people did that. You know, I was just like, "Wow, she works while in the bathroom!" She was constantly, constantly, constantly on the go doing stuff.

Cowan: How did you meet her?

Billings: I don't remember. [laughter] I knew her in 1974 when I went back to Washington, D.C. and spent a week, maybe, with Judy. I arrived there the day that Nixon resigned.

Cowan: Oh, wow.

Billings: So I got to go into the Senate with her and there were offices where people were crying and there were offices where people were partying.

And then I spent some time with Kitty Cone. She was back visiting her aunt and uncle. He was a representative from, I can't remember the state, but they lived in Maryland. They were--in my eyes--extremely wealthy people. Her uncle had to leave early to go to Gerald Ford's swearing in--it was just fascinating.

Cowan: What an amazing time! You knew Kitty before, then, too.

Billings: Oh, yes, I knew Kitty from CIL.

Cowan: And what was Kitty at CIL?

Billings: I don't remember. I remember her mostly as being a Young Socialist and so I'm thinking that she had something to do with advocacy, but I'm not really clear on that.

Cowan: Back to Judy then: you were working for her and you got to make these trips with her?

Billings: Right, and I also did research for laws that she was looking at or different things like that, so that was fun for me.

Cowan: Where did Judy fit into the hierarchy of CIL?

Billings: She was the assistant deputy director, I believe. If it was deputy director was the top, then she was just under that.

Cowan: But Ed was director.

Billings: Ed or Phil.

Cowan: Yes, or Phil.

Billings: I believe. She was never director when I was there that I remember. Her expertise and her area was pretty much law and political kinds of things.

Cowan: Do you remember anything about Ed's management style or what he was like as director?

Billings: His management style seemed to be more--he was very different from John. Ed would give people responsibilities. He would have ideas and try to move them through and get people to make them happen. John was a little more dictatorial. [laughter] I think.

Cowan: So Ed could delegate.

Billings: Delegation--that's it. That's the word, yes. And people were quite loyal to him. I remember Laurel [Sullivan Rexford] followed him to Sacramento. Of course, she was probably somebody he wanted to take with him, too.

Tensions Within CIL

- Cowan: Were there problems within the staff? Were there tensions between people who were in management who had disabilities and people who didn't?
- Billings: I don't know about that. I would assume there were, because there were tensions always. There were tensions between the different disability groups, there were tensions within certain sections of the organization, or between sections--you know, this section has more space or more money than we do. And often that would fall along disability lines, too. For example, blind services would want to have more money comparatively. The physically disableds usually got the lion's share, I think. It seemed that way. And then the staff became so large that it was impossible not to have tensions.
- Cowan: How large? Twenty-five, fifty?
- Billings: Oh, probably fifty. I don't know, but there were a lot of people there.
- Cowan: Working full time?
- Billings: Full time and part time, yes. It was the kind of place where you could be flexible, which was really nice.
- Cowan: You mentioned conscientious objectors working as attendants. Did this qualify for them as well, to be working for CIL?
- Billings: You know, I think by the time CIL was going, it was a non-issue.
- Cowan: Did you notice sexism in the management?
- Billings: Well, yes. Women were involved but men were always kind of--
- Cowan: In charge?
- Billings: In charge, yes. And there were some vocal women--there were some vocal men, too. There was a lot of competition for positions of power, money or all kinds of things. And every once in a while we needed a Reagan to do something nasty to pull us all together.
- Cowan: And that didn't happen again, did it? Or did it?

Billings: It seems like something happened when we were on Telegraph. I can't remember what it was but something happened that we all rallied together for.

Cowan: Those were unifying things when they happened?

Billings: Yes, oh, yes.

Cowan: How about your salary? Do you remember what you were making then?

Billings: I remember my last salary at CIL because I thought I was rich. I grossed \$666 a month and I was able to put away \$2,000. And I don't know how long it took me but I had \$2,000 saved and I actually took my laundry to be done once. I thought that was just the height of decadence.

Cowan: Anything else on Judy, working with her or for her? Did she stay or did she move on?

Billings: Well, she eventually moved on, I know. She was still there when I left.

She scared me to death of flying. [laughs] She used to recite all the crashes that had occurred at the different places we were flying into while squeezing my hand as tight she could and just sort of having this little nervous breakdown. And I, who always liked to fly, suddenly found myself dreading it and I've never liked it since. Thank you, Judy.

Returning to PDSP

Cowan: Not too much help for you. [laughter]

Well, you left. Can you recall at all why you left CIL and went back to PDSP? Do you have any recollection of what that was like or what had changed by the time you got back there?

Billings: I think it had to do with school because I tried to get into the new undergraduate program in public health and didn't. So I think I was going maybe to a more part-time, more flexible job at PDSP when I went back to school.

Cowan: When you went back there were they still on Durant or had they moved? Were they still above Top Dog or were they over on Channing then?

Billings: I don't think I ever worked on Channing, if that's the place where they are now.

Cowan: Well, not now, but that's where they went next.

Billings: Where are they now?

Cowan: On campus. Do you remember at all if things had changed?

Billings: I don't think John was still there. I think John had gone to Sacramento. I think I did a lot of work for Susan there because I remember doing stuff with her and the residence program at that time.

Cowan: Yes, I think she mentioned that you had worked for her.

Billings: It's all just a blur. [laughs]

Cowan: Well, so many things were going on.

Billings: And then when I left CIL finally, it was because I was pregnant and all I could do was sleep. [laughter]

Cowan: So from going from CIL to PDSP and back to CIL, you don't recall any differences or changing?

Billings: Well, at PDSP the personnel changed, and things got more complicated. There were more staff, there was more money, there were more students to be served, more students with different kinds of disabilities, but it was still working at PDSP.

Cowan: It was still like home?

Billings: Yes, oh, yes, it was always like home.

Cowan: At CIL do you think the community at large got served, or do you think there were people who didn't get served by CIL that should have?

Billings: I don't recall ever having the feeling that people weren't being served. The basis for both programs was support services, because without that nothing else matters. And I think as time went on there was a feeling at CIL, in particular, that maybe there was more time and energy going into what was it called, R&D [research and development], and less for actual services, when maybe that should have been reversed. I think that was one of the things that some people were feeling--like maybe that should change, that research and

development was an end unto itself rather than actually serving people.

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Cowan: Research and development issues became the focus instead of shoring up existing projects?

Billings: Yes.

Cowan: I was going to ask you what were the goals? What was the basis for CIL? Can you say what they were?

Billings: Well, as far as my understanding of it, sort of like Maslow's hierarchy of needs, you have the basic things you have to have: you have to have attendant care, you have to have suitable housing, you have to have transportation and mobility. And then I think after that it would be things like jobs, bigger areas of mobility than the city and county, advocacy--well, that would probably be actually a lower level, to get benefits and so forth.

Peer Counseling

Cowan: What about peer counseling?

Billings: Peer counseling was something that was almost automatic in a sense, just in terms of people being there and helping people who came in. But I think later there was a more formalized counseling, both in terms of independent living setup and in terms of emotional or psychological needs.

Cowan: Do you mean professional people would come in to counsel on those things or that it was still peer counseling?

Billings: I think it was still peer counseling. And of course CIL had people like Judi Rogers, who was an O.T. [occupational therapist], to look at how things could be changed or people who would go in and modify the environment for someone.

So I don't remember professional counselors other than Peter Leech, who we were talking about. He was starting some of the counseling groups: parents of disabled children, partners of disabled people, and so forth, and actually talking about some of the pain rather than bearing it, which I think we did so much at first.

Cowan: Did he have those groups meet on site?

Billings: The mates one did not. Mates--partners, whatever--met, I think, at people's houses. And I'm not sure about the other ones because I wasn't in them. [laughter]

Cowan: So parents of people with disabilities, mates of people with disabilities, and--

Billings: And then just disabled people in general and what were some of the issues that needed to come up and be looked at and dealt with.

Cowan: So group therapy sessions?

Billings: I'm not sure how they did that. But I remember when it began it seemed like it was long overdue.

Cowan: And it was Peter Leech who started it. I think we talked about that off tape.

Billings: I know he was there. He's the person I think of as being the initiator of that.

Cowan: And you feel that should have been one of the basic services?

Billings: Well, it was--I guess you could say--developmental. At the beginning it wasn't even considered, but as time went on and people were dying or od'ing or having horrible problems, you know, it became very clear that it was needed.

Cowan: Did that aspect of CIL grow as you were there?

Billings: Oh, yes. In fact, I think Megan and Hal Kirshbaum had something to do with that, if I remember correctly. I don't know. It was never a huge part, but it became an accepted part.

Cowan: Kind of hard for people to admit in the beginning that they needed help?

Billings: Yes, or that there was pain. There was a lot of denial of pain because we were so intent on saying, "It's okay. You know, you can live a normal life. You can be productive. You can be happy. You can do this, that, and the other." But everybody has pain; you can't get rid of it. [laughter] We were young.

Cowan: Yes, and a lot of that was new thinking, then, too.

Billings: That's true.

Cowan: What other projects do you recall beyond the basic things? I know Susan Sygall started BORP [Bay Area Outreach Recreational Program].

Billings: BORP, yes.

Cowan: Do you recall others?

Billings: Well, one I recall quite clearly was the sexuality stuff that was going on. I remember a film that had four different camera angles. I don't remember who it was being presented to, it might have been health care professionals, but it was on disability and sexuality. It was all these different people involved in sex in one way or the other and then talking about it. And that was another issue that's above the basic survival kinds of things, you know, but it is also part of being human so it became important. Judi Rogers actually wrote a book on disability and pregnancy which is, I think, a landmark sort of thing to do.

Cowan: So this was like another counseling group and the films were shown?

Billings: I'm not sure that it was a counseling group. I think it was more educational.

Cowan: You watched it at CIL?

Billings: No, I watched it wherever it was being shown. It was not being shown at CIL.

Cowan: Do you recall other projects that you wanted to mention that you thought were particularly worthwhile? Or not worthwhile would be just as interesting.

Billings: I would love to if I could remember any of them, but I can't.

Job Development and Training

Cowan: [laughter] What about the employment status for people with disabilities in Berkeley? How were jobs found, do you recall? Was it easy to find a job for people?

Billings: You mean for people not at CIL but outside?

Cowan: Right. Outside. Was it a service?

Billings: Actually, at one point I remember CIL being referred to as kind of a sheltered workshop, that people were afraid that it was becoming just a way to get people jobs rather than actually being a dynamic place. I think every organization probably goes through flux.

I remember people getting jobs but it was pretty exciting so I don't know that it was all that common.

One of the things that happened--well, one of the projects was the computer training program, which I think has been a dynamic wonderful program.

Cowan: Who was in charge of that?

Billings: Neil Jacobson, I believe. They trained people to be able to get those kinds of jobs which don't require a great deal of physical action and so forth. It requires brains.

Cowan: That may still be in existence.

Billings: Oh, it is.

Cowan: Who was director, now that Ed was gone?

Billings: Phil [Draper].

Cowan: What was Phil like as director?

Billings: Phil was a very easy-going guy. Phil wasn't brilliant like Ed or John, or tough and powerful, but he was steady and he had come up through the ranks pretty much and he was a good guy. He wasn't flashy or any of those things. I think that he was just a steady director.

Cowan: He had come from PDSP?

Billings: I guess, but he had worked both at CIL, too, in different capacities. And he had been involved in all these different aspects.

Cowan: Well, how long were you there total, do you think? You left in--

Billings: [laughs] I left sometime in the spring of '76. I started working there probably around '70, '71, but I'm not sure.

Cowan: Yes, well, before we move on to your leaving there, are there things that you'd like to talk about at CIL that I haven't thought to ask you?

Billings: Well, it seemed to explode, really. From that little apartment to Telegraph Avenue was just phenomenal growth. When they moved into Telegraph Avenue there was a whole area in back that wasn't being used that eventually was taken over by all these different projects. So it just kept growing and growing and growing. It seemed like there was always something more to do.

And then there were offshoots. You know, the world disability program, I believe it was called--

Cowan: WID--World Institute on Disability--DREDF, I think, was a spin-off as well.

Billings: Yes. Of course we felt like other places caught on and the word was spread, so to speak. I think we always felt like we were the first ones--that we were it. And I'm not sure that was true, but we sure felt like it.

Cowan: Well, you made the decision to leave Berkeley because you were going to have a baby?

Billings: Well, I didn't leave Berkeley right away, but I stopped working. I had to sleep. [laughs] And then I left after I had her. I left in late winter of '77.

IV RETURNING TO HUMBOLDT COUNTY, 1977

The Disability Community in Humboldt County

Cowan: And you came back up here to McKinleyville?

Billings: Yes.

Cowan: Did you continue to work in the disability community at all?

Billings: I drove for Rachel Cranston, whose name isn't Rachel Cranston anymore. She lived in Berkeley for a while and she was kind of on the edge of the community. She's a blind woman. She was a counselor up here for the regional center and I was a driver for her for a while.

I went into the nursing program at CR [College of the Redwoods] and I was asked to give a talk on disability to my peers, which I did but it was very removed in a sense. It's kind of like a disconnection in a way, although I stay in touch down there. I still have friends down there that I go see.

Cowan: What about what's going on with people with disabilities up here? Where do they go? Is there a center for independent living around here that you know of?

Billings: Yes. Let me get the phone book out. I can't remember the name of it. [laughs] It's not a really big place. This is not a big county in terms of the number of people.

Cowan: But there is a place for them to go?

Billings: Yes.

Cowan: What about the attitudes in this community toward people with disabilities? Do you notice that there's discrimination or marked prejudice?

Billings: I think they're more invisible.

Cowan: More invisible?

Billings: Than prejudiced against. You don't see that many people in wheelchairs and if you do it's usually not the dynamic kind of vision that you see in Berkeley where people are out and taking charge. So it's still backwards in that way here, but there is some consciousness.

There's a lot of work with the deaf here. One of the schools in Eureka teaches sign language to everyone.

Cowan: Really!

Billings: Yes.

Cowan: A school or a college?

Billings: No, it's an elementary school. The adult school, the parks and recreation--there's always sign language classes being offered there. But there's not a whole lot happening. This is not an extremely accessible place to live.

Cowan: I was just going to ask you about accessibility issues here.

Billings: The transportation would be horrible and you'd have to have a van if you were going to live here, probably. The university is quite hilly.

There are disabled students' programs both at the university and at the community college--College of the Redwoods--but I'm not sure how much of their population is physically disabled. I know they serve a lot of people with learning disabilities, too.

Final Thoughts on the Independence Movement

Cowan: That's interesting. Well, looking back, then, over your whole time in this movement, what are your thoughts on it? Why, for example, do you think it really happened at Berkeley?

Billings: Well, I think there are a couple of reasons. One is that Berkeley drew these brilliant, assertive (I guess you'd probably call them), dynamic people to it, just by the nature of being Berkeley, perhaps. And the time was right. There was

rebellion everywhere and this was one of those rebellions that turned out to be not only productive and positive, but what society needed all along, so it seemed like it was fairly quickly integrated. I'm sure it wasn't quick enough for us at the time but things have been just accepted there: "Yes, that's the way it should be." So, but it was exciting to have the fights, too, to have to fight for whatever we did. It wasn't effortless.

Cowan: What do you mean by that?

Billings: Well, it wasn't like we just said, "Excuse us, we need this," and they said, "Oh, well, okay." There had to be a lot of talking, showing, legislative battles, and so forth, and demonstrations.

Cowan: Would you compare it to the civil rights movement?

Billings: In a sense, because I think one of the things that had to be done was to make people visible and for politicians, for example, to realize that they had a vested interest in being responsive to this part of their constituency.

I don't think it was as hard a struggle as the civil rights struggle because those prejudices while they may not run deeper, are harder sometimes to overcome. There is the sympathy factor in this one. Sometimes that sympathy factor which can be so disgusting in a way also opens the door for things, so I think they have a lot of parallels.

I remember once, in Washington, Judy and I were there for a conference, watching TV one evening flipping channels. One channel had a telethon going on for kids with cerebral palsy. The people handling it were appealing to the sympathy of the audience to raise money for their organization. Judy watched it just long enough to raise her ire to the point of calling the telethon number and telling them they were hurting disabled people by perpetuating this image of cute helplessness and appealing to the subconscious feelings of relief that, "It's not my child who is so afflicted." I think what sent her over the line was when one of the announcers said, "Remember, 'cerebral' rhymes with 'terrible'."

That whole mindset was something that was constantly being fought in order to have disabled people seen as being wholly human. At this particular time in history, however, what I call "the sympathy factor" could be used at times to open doors. When or if someone said, "Let's let the poor cripple speak," at a housing or transportation or employment meeting,

what began as something done for the wrong reasons changed radically as those on committees or boards or governing bodies were forced to recognize the knowledge, power, and creativity of these disabled people advocating change.

- Cowan: Would you say there came a time that it changed--definitely changed--from a group that needed services to a group that saw it as a right, as a civil right, to have these things like accessibility? Do you think that happened at a certain time?
- Billings: I think that was always in the background that this is a right. I'm not sure when it changed so that that was accepted by more people, but I definitely think that was part of the passion behind getting this whole thing going in the first place.
- Cowan: Certainly by the time you were working with Judy?
- Billings: Oh, yes.
- Cowan: She was back there [Washington, D.C.] addressing it as a right.
- Billings: Sure.
- Cowan: But when you were at PDSP were people still thinking--I mean, do you think they were thinking that this was a service request?
- Billings: Just kind of a little extra?
- Cowan: Not a demand for the right to have it?
- Billings: Maybe the office, itself, but you know, I don't see how you can see attendant care as anything but a necessity or a right, just in terms of seeing the person as a human being.
- Cowan: Well, you were in a unique position that you have been married to a disabled person, that you worked as an attendant, that you worked at PDSP, and you worked at CIL, so your reflections are valuable.
- Billings: Thank you.
- Cowan: Well, do you have anything else to say on that subject before we finish up, or on any subject?
- Billings: Well, I probably will. [laughs]
- Cowan: You'll be able to add a paragraph to this.

Billings: Oh, okay. One paragraph?

Cowan: Or as many paragraphs as you like.

Billings: I'm much better at writing than I am at talking.

Cowan: In your view, though, things really have changed over the time that you've been there, just in terms of accessibility and discrimination changing and all of that?

Billings: Yes and, in fact, if you drive through Berkeley now, there are people in wheelchairs everywhere! And we used to remark on that: "Look at all the crips! [laughter] Where'd they come from?" Now there are even more, so I think it shows that if you build it they will come. [laughter]

Cowan: All right, well, anything else, at all?

Billings: Not right now.

Cowan: Oh, well, then thank you. It's been a wonderful interview. Thank you very much.

Billings: It was fun doing it.

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BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II

Michael Fuss

ATTENDANT FOR COWELL RESIDENTS, ASSISTANT DIRECTOR OF THE
PHYSICALLY DISABLED STUDENTS' PROGRAM, 1966-1972

An Interview Conducted by
Sharon Bonney
in
1997

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INTERVIEW HISTORY--Michael Fuss

Michael Fuss started work in the Cowell Hospital program in 1966 with the first group of students with severe disabilities who enrolled at the University of California at Berkeley. He was involved in early discussions with students about the independent living concept and helped establish the Physically Disabled Students' Program (PDSP). He became PDSP's first assistant director under John Hessler. Mr. Fuss also was involved in formation of the Center for Independent Living. Mr. Fuss' interview is important because of his direct involvement with the independent living movement and his knowledge of the events which occurred in the early years. The interview also gives valuable information about Ed Roberts, John Hessler, and others in the movement.

Michael Fuss began work in the Cowell Hospital Program to support himself and his wife while he was attending the university. He paints detailed pictures of John Hessler and Ed Roberts as individuals and as developing leaders. A large part of the interview explores the development of the Rolling Quads in response to pressure from the California State Department of Rehabilitation to make several students "shape up" or be thrown out of the program. His interview talks about how the students sought sponsorship of 199 courses on disability and taught the courses, how they educated and empowered themselves, and how they became a political force to be recognized and respected.

Once they became empowered, the students began working on the establishment of PDSP. Ed Roberts went to Washington to work on legislation that provided the first funding for disabled student services in higher education settings. Mr. Fuss discusses establishment of PDSP, the services offered, attempts at coalition building, the interactions between people with disabilities and people without disabilities, and his eventual leaving. He also describes how the seeds for the Center for Independent Living (CIL) were sown at PDSP and how office space was set aside in PDSP for CIL services to be provided.

Two interviews were recorded, one on December 4, 1997, and the other on December 11, 1997, in the interviewer's home in Oakland. One pre-interview meeting was arranged prior to taping of the sessions. The tapes were transcribed, lightly edited by the interviewer, and sent to Mr. Fuss for his review. He made a number of additions and clarifications to the document, which was returned on October 29, 1998.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sharon Bonney, Interviewer-Editor

November 2, 1998

Regional Oral History Office, The Bancroft Library
University of California, Berkeley

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Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Michael S. Fuss

Date of birth 3/17/45 Birthplace Brooklyn, New York

Father's full name Milton Fuss

Occupation CPA, Lawyer Birthplace Brooklyn, New York

Mother's full name Carolyn Rhoda Marcus Fuss

Occupation Hypnotherapist Birthplace Brooklyn, New York

Your spouse Judith Susan Breakstone

Occupation Insurance Agent Birthplace Brooklyn, New York

Your children Ilan Fuss, Oakland, CA Aryeh Breakstone, Oakland CA
Rina Breakstone, Oakland, CA

Where did you grow up? Brooklyn, Bronx, West Islip, N.Y. San Fernando Valley, CA

Present community Berkeley, CA

Education UCB AB Anthropology MBA JFK ~~Univ~~ University, 1991

Occupation(s) Proposal writing, small Business Management,
Start-ups of Non-Profits

Areas of expertise Manager Non-Profits, Fund-raiser Non-Profits,
Consultant, Manager, Proposal writing, Lecturer, Consultant
small business. Currently on Disability

Other interests or activities Study of Jewish Texts, start-ups
of necessary non-profit organizations, writing, book packing (which
hiking, Dogs, Internet, Local Newspapers, Magazines, etc from all around the world. ^{legal}

Organizations in which you are active Telivah Day School, Congregation
Machat Shalom, ABSC (soccer) political campaigns.

INTERVIEW WITH MICHAEL FUSS

ATTENDANT IN THE COWELL RESIDENCE PROGRAM ATTENDANT AND ASSISTANT
DIRECTOR OF THE PHYSICALLY DISABLED STUDENTS' PROGRAM, 1966-1972

[Interview 1: December 4, 1997] ##¹

Early Years: Civil Rights Activities and Education

Bonney: Michael, maybe you could start out by telling me a little bit about your parents and your family, where you were born--sort of background history on you.

Fuss: Okay. I was born in Brooklyn in 1945. I lived in Brooklyn and the Bronx, and then on Long Island, and then in Los Angeles.

Bonney: How old were you when you came to Los Angeles?

Fuss: I was fourteen when we moved to L.A. I have a brother and a sister. My brother is nine years younger than me. He has spina bifida. I have a sister twelve years younger than me.

I finished high school in Los Angeles. I worked after high school for the Southern California Gas Company, running their mailing machine and mailing unit. They had to mail out the bills and all that, and I ran the machine. I kept the machine going and the supplies coming in and fixed the machine and stamped all the bills for all of Los Angeles.

I also was at that time organizing for CORE [Congress of Racial Equality], both at the Southern California Gas Company, where there were a number of blacks who were basically in janitorial positions only, and in an area called Pacoima, in the San Fernando Valley. It was the only place in the San Fernando Valley at that time that blacks were allowed to live.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Bonney: Now what was this association?

Fuss: Congress of Racial Equality--CORE. One of the founders was a man named James Farmer. It was founded in the late forties, I believe. It was at that point an advocate of nonviolent change for civil rights.

Bonney: What got you involved in that at your early age?

Fuss: I had been involved in politics since I was probably twelve or thirteen. I was in youth groups and various other sorts of things, which got me interested. I read a lot. I was concerned about nuclear war, I was concerned about the inequality in the country at that time between blacks and whites. I was involved in a number of civil rights and other organizations. So even at that time I was an organizer. I was involved with sit-ins at a restaurant chain called Van De Kamp's, which refused to hire people of color even for dishwashers, any kind of position. We eventually forced them to open their employment. I was involved in organizing in Watts, prior to the Watts riot. I was involved with a group at that time called the Friends of SNCC [Student Nonviolent Coordinating Committee]. We were concerned about a number of things, one of the major issues that summer was the disappearance of civil rights workers in Mississippi, who were killed. We didn't know that right away; we suspected it. I was involved in trying to generate publicity about that and trying to help form organizations that would promote civil rights, or as we called it, equal opportunity. Then I started going to junior college at night.

Bonney: Which college did you go to?

Fuss: Pierce Junior College, and then I worked out a deal with the gas company, where I became an assistant mechanic. I worked at nights--gassing, lubing, doing oil changes on all their vehicles, and went to school during the day at the junior college, and then I transferred to Berkeley.

Bonney: What was your major in the junior college?

Fuss: My major at the junior college was math. But by the time I transferred to Berkeley it was anthropology.

Bonney: Now when did you come to Berkeley?

Fuss: I came to Berkeley in the summer of '66.

Bonney: And did you live in the dorms?

Fuss: No, I never lived in the dorms. I was twenty-one at that time. I lived across from the dorms and rented a bedroom in an apartment for thirty-five dollars a month, about three blocks from campus. And one of my roommates was Chuck Grimes.

Job at Cowell Residence Program

Bonney: Did Chuck Grimes get you involved in the disabled rights movement?

Fuss: No, it was the other way around: I got him involved.

Bonney: Tell me about that.

Fuss: I was earning my way through college and got married, so I was supporting my wife and myself. She was on a scholarship, and we needed extra money, and I didn't have any other means of support, so I was working. The job I ended up with--in fact, I had a variety of jobs--was working as an attendant up at Cowell Hospital. I was talking to Chuck one day, and he was looking for work--he had been doing all sorts of things, like carpet laying and carpentry--and suggested he might want to come up and work there too.

Bonney: What did you do at Cowell Hospital?

Fuss: I started out as an attendant to Scott Sorenson and John Hessler. I worked occasionally for Ed Roberts, and for other people off and on. But John and Scott were the people who I basically took care of, and it was mostly John. I'd come in the morning, and I'd come in the evening. He had other attendants also, but that's how I got involved and got to know John and the other people up there. I was up there a lot.

Thoughts on John Hessler

Bonney: Tell me about John. What was he like as a person?

Fuss: John was a complex person. A very interesting guy, who I liked a lot. I think his background tells you a lot about him.

He comes from a working-class family. His father was a Teamster. John was a hellraiser as a teenager, which is how he broke his neck. He was very physical and not very involved in

school, and I think he would have led a life much like his brother, hunting and working in more manual labor type of jobs, if he hadn't broken his neck. There was a strong core of--I think that most people felt but didn't understand--a potential violence, because John was very tall, very big. His whole family were big men. The way they got their ways and settled problems was by threat or actual violence [chuckles]. That was one of the techniques that was used. I think that people picked that up on an unconscious level when dealing with him. That was very helpful to him in getting his way.

On the other side, John was a poet. A published poet. A life of the mind. A literary intellectual. A French major--he loved the sound of French coming out of his mouth and reading it. I think that he took as a model, in many ways, to live a French model, which is that you basically worked as a bureaucrat or some other kind of job where you can do some good during the day, and you had your real life outside of that: talking about literature, writing poetry, doing politics--whatever your real life was outside of your job. But you needed and wanted a secure position someplace [chuckles].

Bonney: What kind of poetry did he write?

Fuss: I don't remember clearly. It was very sensual. That's what he liked. John was a very sensual person. The senses were very important to him. Being a quadriplegic and not having much awareness in most of his body, I think he developed an ear and language to compensate for that. The sound of his poems, I think in some ways--at least as I remember--were much more important than the content. He was a very bright guy. He was basically also somewhat conservative. He and I had great arguments for years about politics; at that time I was definitely well left of center. We argued about politics. One of his other attendants was someone who was very involved in martial arts. I used to come in, and the guy had put up faces and had been practicing jabbing for the eyeholes [laughs] while taking care of John. He eventually joined some of the elite forces in Vietnam. That was his goal: graduate from college and do that, become an officer.

John and I discussed politics a lot, and I was active in various movements on campus and tried to talk about connecting them in some way to a situation he found himself in. But basically I think he was just well grounded in his beliefs. He was not ever tempted really to be an extremist of any kind, though his family was certainly full of bigotry. John invited myself and my wife to go to his house for Thanksgiving. They shot pheasant and quail, and had an interesting sort of thing, but his father

wouldn't let me into the house because I was Jewish. I remember that being a real conflict for him.

Bonney: How did John handle that? What did he do?

Fuss: He told me--I mean, it was before we went.

Bonney: Oh, you weren't at the door.

Fuss: Luckily it wasn't at the door; it would have been much more traumatic then. But we were all prepared to go, we called him up, and he said, "It sort of slipped out that you're Jewish, and my father was enraged." It's interesting the only other Hesslers I've met are all Jewish [laughter]. And he certainly had the nose, that stereotype [laughs].

Bonney: John's public life--to bring in the food and stuff--was the bureaucratic side with UC. There was the poet at night and the bureaucrat during the day. Tell me about John the bureaucrat.

Fuss: John the bureaucrat. What's real hard is differentiating in lots of ways. We were a real team--it was Larry Langdon, John, and myself. We were a real management team. It got to the point where we would write reports or recommendations or grants, and we couldn't tell where one person's writing stopped and the other person's took over. We really did mesh in some very profound kinds of ways, so it's real hard to pull out.

Early Independent Living Concepts

Bonney: Let me back up a second to how you got from being John's attendant to being a co-manager with him of PDSP [Physically Disabled Students' Program].

Fuss: We've got to back up then. Over the years we talked more and more about the future, and as the program expanded up there what should be done. I think that John and Ed and a whole number of other people up there [at Cowell Hospital]--a lot of them, not all of them--really felt grateful for the opportunity, but also very constrained by the limitations.

Bonney: Of living in the hospital.

Fuss: Of living in the hospital and being under a medical model, and of being actively discouraged from attempting to live on their own. Nurses would come up from the floor down below, and it was helpful

to have the nurses if somebody was in trouble at night. But also they'd come up and tell people to be quiet or they'd start ordering people around like they were sick. Well, these guys weren't sick [laughter]. They had disabilities of one kind or another. Most of them were quads--not all of them. They were healthy, late adolescent to early adult, mostly males--though we had two women eventually--who wanted to be like everybody else and explore their life, explore possibilities. Don't forget the time. This is the middle to late sixties, and everything was exploding, everything seemed to be possible, you could do anything you wanted, that was the whole idea. So we talked a lot. There was a certain recognition on the part of the hospital administration that something had to be done as the program got larger. So they hired a nurse--

Bonney: Who was it?

Fuss: Eleanor Smith. I became her assistant, which put me in a position where I helped interview and do ongoing training with attendants, because that had always been a problem: we'd get these people who wanted to work, but then they had to completely train them from the beginning. So I did training with attendants. I was there for like three hours a day so that I was available for anyone to use without having to use their attendant money to hire somebody. So I was available. They put me in a position where I was really there. We talked, and a whole bunch of ideas started coming up about what to do. I think my experience in organizing--because I had started a number of programs and had been involved in a number of things in the past--and my connections to the organizations on the campus that were trying to change the world at that point brought a certain advocacy and a certain style and a certain direction, and a belief that something could happen.

How it all evolved was not simple--it was complex. So we started thinking about it, and the ideas for the Center for Independent Living and the idea first of more of a group home sort of thing run by the disabled themselves--by the quads in this case. Put people in apartments, with a place that they could come for wheelchair repair, and maybe a meal, advocacy with the Department of Vocational Rehabilitation. All that started developing.

Then an opportunity came up. It was well-connected, through the political science department with a lot of what was happening in Washington. There was money coming out, mostly for minority students to develop special services out of the Department of Education that would help people. Its mission was sort of to help develop programs to bring people to colleges and universities across the country, and to provide services for people who had not

had opportunities in the past. There's no reason not to include the disabled in that.

Bonney: Were disabled included in that originally?

Fuss: The original concept did not include disabled. My understanding basically is that Ed had a lot to do with including the disabled in the program. A certain set-aside [Federal TRIO Special Services Funding]. It was all set up. It was set-asides, so there was a certain amount for Appalachian whites, and there were certain amounts for Puerto Ricans, and there were certain amounts for Mexican-Americans, and there were certain amounts of blacks. And then there became certain percentages for programs for the disabled. So we had to figure out what we were going to do.

The first step we did was to set up courses so that people living in Cowell could work on this and get credit for it. So we set up independent student courses, which were 199 courses. One every quarter. Sometimes they would be in the sociology department, sometimes in the political science department. In those courses we did a number of things. The courses were taught primarily by John and myself. Ed was gone by this time. The person he was contacting--I forgot the woman's name--

Bonney: Jean Wirth?

Fuss: Yes, Jean Wirth. They got involved in a very different project. They were setting up a college called Nairobi, which was a two-year community college in East Palo Alto. Most of his trips to Washington seemed to be around that. Ed moved out and was teaching there. He was part of that project. So Ed was gone. John and I basically taught these classes. We just went into things like self-identity, what does it mean to be stigmatized because you're in a wheelchair? How do people treat you? What do you feel about yourself? How did this come about being? What can you do about it? What do you feel like doing about it? What are the barriers in the way of becoming more independent? Architectural barriers, social barriers, political barriers, attitudes of teachers at the university, not enough money for people with other kinds of disabilities, and what kind of help they need--special equipment. Then we started exploring the limitations of how far we could push Rehabilitation through advocacy. I took a number of cases and pushed on that. One of the things we took was like Hale Zukas, who was not involved with us at that time. His mother hired people to push him around campus and getting him to want a power wheelchair, and then when he wanted one, fighting the battle to have it paid for because it was not cheap.

Bonney: Do you remember in Hale's case if Rehab paid for his chair or Medi-Cal?

Fuss: Interesting question. No, I don't remember.

Bonney: He doesn't quite either, and I'm trying to clarify that.

Fuss: We always went both routes and let them fight it out [laughter].

Bonney: Let's go back to the course for just a minute. You said that you and John mostly taught the courses. How did you guys get so smart in all these areas?

Fuss: Somebody had to step up, that's one of the issues. John had a bachelor's degree and had a year of independent living in France at that point--this was after he came back. He was the recognized leader up there. I had experience in organizing and how to create a sit-in, how to create change. I was also older than most people there too. Somebody had to do it. If we had brought in a professor to do it, it would have been an academic class. That wasn't what was of interest; we were interested in the academic information, but how to use that in practical kinds of ways.

Bonney: How did you get it accepted into, say, sociology or the poli sci department?

Fuss: There was this class of courses called 199. They were independent study courses, basically. Any professor could sponsor students in 199 courses. We would approach a professor--and Ed was very helpful in doing that and telling us who to do it with--with a course outline and with books, and then John and I would do the research and give them a course and tell them what we were doing, and they would say, "Oh, sure."

Bonney: Can you remember some of the professors that supported the courses?

Fuss: Offhand, no.

Bonney: And students got--

Fuss: So the students got five credits for the courses.

Bonney: Five credits a semester.

Fuss: No, a quarter.

Bonney: Was it open to students other than just the students at Cowell?

Fuss: It was just open to the disabled students. There were some who took advantage of it and didn't do much of anything and sometimes didn't bother showing up; they were going to get a good grade [chuckles]. But a lot of people really participated, and I think this raised the awareness of what the problems were and created a lot of ferment in terms of how to solve things and the direction to take. I think as this happened and people started living more independent lives--and in some ways doing riskier things, like trying drugs and having sexual partners--it started really bothering the nurses downstairs and, therefore, the hospital administration. They started trying to institute more restrictive curfews.

Rolling Quads Formed in Response to Growing Pressure

Bonney: They invoked curfews?

Fuss: All sorts of things. That created a reaction and created the kind of atmosphere in which people realized they needed something by themselves. It fed that. The Rolling Quads were formed at that point.

Bonney: What were the Rolling Quads?

Fuss: The Rolling Quads were basically the guys up there--

Bonney: Were the women involved?

Fuss: Yes. "Guys" for me is an inclusive term. I use it with my kids, and my daughter sometimes complains [laughs]. It's become gender-neutral.

Bonney: Why did they form?

Fuss: They formed because there was a certain striking back about this. There was more pressure from vocational rehabilitation, from Lucile Withington, on people not spending enough time learning or not taking schoolwork or the appropriate courses.

##

Fuss: People wanted and needed an organization which could stand for them unified. There were basically two people they chose out to eventually come down on the hardest: one was John, and the other was Donald [Lorence].

Bonney: And you say "they" came down? Was this Rehab coming down, or was this the hospital?

Fuss: Both.

Bonney: What did they do?

Fuss: John at that point had two quarters left for his master's degree, and they said that they would support him for only one more quarter, and then he would have to leave and not receive any funding from Voc Rehab to go further. Since he already had a bachelor's degree, there didn't seem to be any sense in them supporting him to a master's. Donald had seen a therapist, a psychiatrist, at the Cowell Medical Center, because he had some adjustment problems coming from--there were very different kinds of adjustment problems that you could see from people who have injured themselves in adolescence and people who had been born with whatever disability they have. He had been born with it and had a very sheltered upbringing, and then coming to the campus--he had never had anything resembling a normal life. He had been seeing a psychiatrist, and clearly information from the psychiatrist had been given to the hospital administration. That psychiatrist eventually got disbarred over another issue.

Bonney: Do you remember who that was?

Fuss: Paulsen was his last name.

Bonney: Do you know his first name?

Fuss: No. He's no longer living; I know that.

They tried to intimidate him and kick him out.

Bonney: What were their issues with Don?

Fuss: I would say his flamboyant lifestyle. He took on kind of a hippie air: he wore wild clothes and let his hair grow frizzy, he didn't make any gestures toward hiding--I don't think he was doing much of anything that other people weren't, but he didn't hide it [laughs]. So there was an attempt to just remove him from the program. So he was made president of the organization. Then they really got nasty, and Eleanor Smith abruptly left. She picked up all her case files, all the information on everybody up there, and disappeared one day. Just disappeared. Voc Rehab, through Lucile, started giving problems. Before that happened they brought in one new person who, if I remember right, was an ex-military person they sort of expected to take over. At least this person came in and started taking over.

Bonney: The hospital hired this person?

Fuss: Oh, no. He was a quad. It was a quad that they brought in.

Bonney: Who was he?

Fuss: I can't remember his name; he wasn't there very long. There was all this nastiness coming down from Vocational Rehabilitation. There were all these threats, medicine cut-off. "We're not taking care of you." The nurse on board replaced the nurses from downstairs, so the nurses from downstairs have been told they have no responsibility up there, so they are not to come up there. Eleanor left without saying she was sick or anything. She just disappeared after some fairly nasty kinds of interactions with myself and various other people, in which she felt she was being betrayed, and everyone was betraying what she was trying to do. I just saw everyone was just taking what she was trying to do one step further, in terms of rehabilitation, rehabilitating themselves. I think that was kind of the key in terms of group cohesion--it took a little while, but almost everyone came over to supporting Donald and saying, "We've got to do something, we've got to set something up. This can't work this way." There were a few holdouts. A few people just wanted to be neutral and go to school, which was fine. And there were a few people who were very angry at what was going on. One person, as long as he got his Percodan was happy [laughter]. I think that gave it sort of the jumpstart--as a community--out of Cowell Hospital, because people started moving out [laughs].

Bonney: Now what happened to the idea of a halfway house or whatever? That was talked about a lot.

Fuss: It disappeared because people started moving out and surviving nicely, and it was great for them.

Bonney: So the concept of a halfway house was sort of a--

Fuss: A halfway measure [laughs].

Bonney: Sort of a safety net? Once they moved out of Cowell they would live in the same building or whatever, and if they needed help someone might be around.

Fuss: Right. The idea was sort of taking the Cowell project and transplanting it out into the community. Somewhere that just disappeared. I think it disappeared because people took this next step beyond, saying, "I don't want to live that way; I want to live the way I want to live. I can have attendants, people as roommates so they can pool their attendant money to make sure that

they were covered." But they got to choose who they were roommates with.

Grant Proposal Written for Physically Disabled Students' Program

Fuss: At the same time, the grant requests came out--the RFP's came out. The Requests for Proposals. So we started writing a grant for this.

Bonney: Now who was "we"?

Fuss: "We" was the class, and people had different assignments to do different sorts of areas. Then basically the writing turned out to be Larry Langdon, myself, and John. We ended up doing the bulk of that work, with Donald doing a lot of idea creation and help. Then it turned out that none of us had ever written anything like this before, so it wasn't going to fly, and it had to go out in the university's name, and they wouldn't put it out. Arleigh Williams, who was the dean of students at that time, was very impressed with Ed, and John met him through Ed. John went down there and talked to Arleigh, and they went over it. Arleigh came up with this guy named Ray, who was in public health, who was from New Zealand, and who had written a lot of grant proposals. Ray took our material, talked to us, and then put it into the right format and showed us how he did it. He was at UCB for only like two years; he went back to take over the public health for a number of islands that New Zealand administered under U.N. trusteeship.

Bonney: Do you remember Ray's last name?

Fuss: His last name? He was Ray. He came in and said, "Hi! I'm Ray from New Zealand! Arleigh sent me over." [laughs] We then did some revisions to it, it went to Campus Development, which is--you know [laughs] the way those things go in Campus Development. We sent it off, and it went on, and it was funded.

Bonney: You mentioned that when you originally started talking about the concept and moving out and having something in the community, you were talking about a Center for Independent Living concept. How did the first grant change from a CIL concept to a PDSP?

Fuss: As I later learned writing lots of grants in my life, grants never give you what you want; you've got to give them what they want. So what this was oriented toward was universities, and it was for providing special help to people, to recruit them into

universities and support them through--academically mostly. We expanded that, of course, because of the special needs of the disabled, to include other kinds of supports. So we replied to what was there, and we said, "Yes, there's the first step. We can start doing something, we can start removing architectural barriers and many other services and actions." As a matter of fact, John and Larry and I sat down after it was funded, and it was a good program. It was oriented toward the students, and we really felt like we could implement it and really help all the students and bringing students in from all over. We had money in for recruiting at that time. We also decided to put me in charge of non-university CIL type of activities: setting up advocacy sorts of things, political organizing, doing things in the city, doing things for non-students--all of that sort of thing. I was put in charge of that.

Bonney: Was that as your role as assistant director of PDSP?

Fuss: Yes, as one of my tasks.

Bonney: And John ended up being the director of PDSP.

Fuss: Yes. John ended up being the director, I ended up being the assistant director, Larry ended up being the counselor coordinator. And we gave ourselves six months before the university cracked down. We said, "No one's going to notice us or do anything for at least six months." Full bore, out there for six months, then we'll deal with what happens.

Now this gets to the role of John as bureaucrat. John--deep, resonant voice--had a real presence. Very controlled. I don't think anybody in the university ever saw him lose his control; I have [laughs]. He's reasonable, forceful, very clear mind--he had his objectives all in mind. We decided my role with the university was to continue my role as agitator. When we were having problems, I would go in first and ask for everything and be extravagant and crazy and do that sort of stuff. Then John would come in with what we really wanted, as the peacemaker. I guess it was a form of mau-mauing, [laughter], and it was very effective. Behind me was the threat of students coming in in wheelchairs and sit-ins and all that sort of thing [laughs].

Bonney: Which they didn't want.

Fuss: Which they definitely did not want. They had enough problems with healthy people, physically whole people being arrested and having sit-ins that caused them problems.

It was also a very interesting time in the university's history. It was being run by a bunch of people at Rand at that time.

Bonney: The Rand Corporation?

Fuss: Yes. The chancellor [Mr. Fuss is probably referring to Charles Hitch, who was president of the University of California Statewide System at this time] had been working for Rand for a long time. Some of the people he brought in were ex-Rand people. They had a real secrecy fetish. They were real brilliant, and they were trying to work five-year or ten-year kind of timelines, but they never told you what they were. So one of the things we always had to do was, "Where did they see us as fitting in?" We never knew; it was like a game. It was like the board game, Battleship, where you don't see the other person's side. You each have a fleet of boats and you say a position and they say whether you hit something or not, and you basically find out by misses and hits and you can draw a diagram in your head of what's going on. Well, that's how we had to work the university. We would always be floating future suggestions, growth patterns, things like that. Not so much that we wanted some of them, but to find out whether we got hits or misses [laughs], whether we're told, "No, that's not in the works," so we would know the university doesn't want us to be there or they have something else planned for that. Or "Oh, there's room there? Okay, what can we do there?"

John and I also decided on the strategy that the people who really got things done in the university were the administrative assistants who were all women at that point. John was very charming, and I had an appeal to certain kinds of women too, and so we just had this whole network of administrative assistants that we developed as friends and had confidence in in asking for help.

Bonney: Do you remember the names of some of these people?

Fuss: No. John was the one who would keep the lists [laughter]. Later in my life I started doing that, but that's gone. Probably when I'm eighty I'll remember all this sort of thing, but not now.

Bonney: How big was the first grant? Do you remember?

Fuss: I have it at home. I think it was about \$80,000. Something like that.

Student Body Tax

Bonney: The Rolling Quads had another source of money, did they not?

Fuss: Right. That came a little later. That came after PDSP came into existence, in which we were all kind of talking about how restrictive money was. The university sort of really put its accounting on us--accountability--and we started understanding that you couldn't transfer between accounts except for minor amounts and all that sort of thing. We were all fairly naïve at this point [chuckles]. We were all griping that we didn't have free money--soft money I think it would be called today. At one of these gripe sessions, I have no idea where the idea came up--because there had been an election--the student government at Berkeley was very big at that time, and the student store had a million dollar budget. The students voted to tax themselves to support some program for blacks. So we said, "Hey, why don't we get some money that way?" Don Lorence was put in charge of that. So it was a Rolling Quad effort. The first slogan was "Nickels for Cripples," and then "Quarters for Cripples." I have some posters.

Bonney: They actually used that slogan? They actually used the word "cripples"?

Fuss: Oh, yes. It was an in-your-face--with a guy in a wheelchair.

Bonney: Can you remember the discussions around this?

Fuss: Just as blacks have always used the "N-word" among themselves, toward each other, this group always used the "C-word" toward each other.

Bonney: But this was not toward each other; this was putting it out into the community.

Fuss: This was putting it out there, and it was put out there in a very shocking way on purpose. "Wake up. We aren't this, but we know you think like this."

Bonney: Did it work?

Fuss: It worked. It passed. It was twenty-five cents per student. Considering there are close to 30,000 students--. In 1970 dollars that's a lot of money. That money was soft money; it had no strings attached. It was put in for the use of the disabled community on campus.

The Seeds of the Center for Independent Living

Bonney: So it was used for non-students at that point?

Fuss: It was basically used for the CIL. For starting the CIL. We made space for them in our office, bought office equipment, extra telephones. That money was used for that, and it was also used because we were chipping in to provide money for food. We were making lunches. We were taking turns at least in the beginning of making hot lunches every day.

Bonney: What was behind that?

Fuss: The idea was you come on campus either from your apartment or from Cowell or wherever, and you're in the central part of campus most of the time. You could have a bag lunch, or you can spend money if you had that much money to spend; they were all on welfare. Or you could come to our place and get chili or spaghetti or something hot and talk and socialize. It was a great place where ideas came up, where people met people, where the idea of community was developed and a real community came into being. It brought in people from all over who weren't through the Cowell project. There were a lot of disabled people on campus who weren't through the Cowell project, and we brought them in to know what the Physically Disabled Students' Program was and also increase our awareness of what some of the other kinds of disabilities were and what the problems were and how to deal with them and what was needed. So it was a real great, direct kind of way. John and I and Larry almost always had lunch there, so we were just available all the time to throw ideas out and see whether they flew or to get gripes back or new directions back. It was great feedback.

Early Physically Disabled Students' Program Activities: Liaison with Blind Groups, Curb Cuts, and Politics

Bonney: You talked a little bit just now about other groups. I imagine you mean other disability groups.

Fuss: Right.

Bonney: The original PDSP focused on quads or people in wheelchairs.

Fuss: It focused on the severely disabled, except that one of our first hires was somebody who was blind.

Bonney: And that was?

Fuss: David Konkell. In that first six-month period David and I worked on a strategy for trying to get the blind more involved in what was emerging as a disabled movement rather than them going their separate way which they had been doing for a long time. They got more money per month, and I think that's still going on. Then we helped organize and brought some money in and stuff like that for the young Turks and a proposal center for generating motions on the floor to cooperate with other organizations representing other people with other kinds of disabilities at the annual blind meeting. We had a hospitality room.

Bonney: What's the annual blind meeting?

Fuss: I forget which organization it was, but there was an annual meeting of--

Bonney: Like the National Federation of the Blind?

Fuss: Yes, but it was northern California. And we helped organize a lot of students to go to it.

Bonney: Was this in relation with the blind/deaf school on campus?

Fuss: No, it wasn't on campus at that time. This was in combination in terms of creating alliances for dealing with Voc Rehab and welfare and political issues.

Bonney: So it was a group that met from northern California with DSP--

Fuss: No, this was their annual meeting. They had always disdained having any kind of contact with other disabled groups. So I went to it, though I was in the background. David was there and did most of the talking. It was really to get the word out that people needed to work together, that it would be more effective to work together, and that things were happening in Berkeley, that you could make a profound change. It was time to have some kind of change. We were a bunch of young Turks, as the saying goes, who were interested in this kind of change. So we got them connected with each other and with us. So that was one of my outside directions.

The other outside direction--which in some ways I think I'm most proud of in some kind of strange way, because I see it all the time, I guess--is that we have been talking about architectural barriers. One of the main ones were sidewalks. So the summer of '71, I guess it was, Ruth Grimes--who was married to Chuck--had just finished her first year at the school of urban

planning and needed an internship. So I said, "Sure. Come with me; I have a great project for you." Right up the alley of the school. By that time Fred Collignon was interested in coming by and stuff, so he gave permission that she could come over and that would be an okay internship.

Meanwhile, I had brought Chuck over to work on wheelchairs. That was one of his talents: mechanical fixing and all that sort of thing. I brought Chuck over. He was working under my supervision. I couldn't have Chuck and Ruth working under my supervision, so we put him under Larry's [laughs]. Not that it meant anything; I mean, it was lines on the chart. We're not working that kind of way at that point. We were still in our infancy; you don't need that in infancy.

I gave Ruth the task to look into ramps, design ramps, and then politically pressure the city to pass regulations to install the ramps.

Bonney: Now when you say "ramps" you mean curb cuts.

Fuss: They turned out to be curb cuts; we called them ramps. Ruth did a terrific job. It was a big job. Of course it was money--and I don't know how aware you are of it, but the engineers fought it tooth and nail. And to develop engineering specs she really had to--all sorts of things she had no idea about, and find sympathy from people to come up with engineering specifications.

Bonney: Did she focus just around campus with this project? What was the scope of her work?

Fuss: The scope of the work was to basically set up mostly around campus. The first step was around campus, but then to design a plan for the whole city. To have a five-year or ten-year plan--we had no idea how long. She needed to figure out what was politically feasible, how to put it in, and to prioritize. We set up committees of people in wheelchairs to work with her, to say where the priority corners were in downtown Berkeley and on Telegraph and down University Avenue and wherever. It was a really comprehensive program. She worked on it there, and then she continued to work on it after the internship was over during the summer. I was supervising it; I wasn't terribly hands-on. She was carrying out most of the work, but she'd come back to me for help on particular strategy in dealing with the politics. Then when we finally started getting public hearings, she said, "This is a public hearing, what do I do?" I said, "Well, we need bunches of people in wheelchairs there making lots of noise. Here's a list: start calling [laughs]. Tell them what's happening and let's get them there." I said, "You also need to start

getting some people to talk to the various council people." I essentially told her how to run a political campaign. I sat down with her and helped her plan that out. Then she started doing it. She worked on it part-time, all year round, and I think she got some credit for it out of the school. She really was the person who did it. That was real exciting. It was real exciting to be involved in and win fighting a real political fight. And then to back it up there was a new coalition called the April Coalition, which was a coalition of people on the left [in the City of Berkeley] coming together.

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Fuss: The BCA--we won't go into the background of why it got formed, and the [Robert] Scheer campaign and all those sort of things. There's all sorts of stuff in The Bancroft Library about that, I know that. Hale Zukas and I thought, and we decided we needed a disabled workshop and then a plank. So we set up a disabled workshop, which we ran.

Bonney: Which was part of the April Coalition?

Fuss: The April Coalition. And out of that, not many people came. Basically Hale and I wrote a whole number of issues, which included curb ramps and transportation issues, addressing issues of transportation, and addressing issues of welfare and Voc-Rehab, and various other kinds of things, which I have at home too. So from a political end, at that point, that was, I think, the first time, on an overt level, that the disabled movement was sort of getting hooked in with a political movement. It committed to at least a large measure of the immediate physical objectives that we [inaudible]. Thinking back from this position, it's too bad that it had to be the most left group, but those were the only people at that point who were interested.

Bonney: People from what was to become the BCA did come to this meeting?

Fuss: No, they didn't come to the meeting. Some people came to the meeting, but they accepted the plank, so it was part of the April Coalition's platform that year. It had an actual platform on serving the disabled community.

Bonney: What happened to that platform? How did they use it?

Fuss: That I don't know, because that came later. I was gone by that point. That was tending toward the end of my involvement.

Bonney: What year was the April Coalition meeting?

Fuss: The April Coalition would be probably for the '72 elections, so it probably was the summer of '71. That would be my guess. The elections were generally in June.

Bonney: Let me go back just a minute. You mentioned Professor Fred Collignon around '71 or so was becoming somewhat involved. What was his role or what did he do with the movement?

Fuss: His involvement really was later. He was around for a while making all sorts of promises, none of which I saw anything happen with. But I do know that he got involved. What he did I don't know; I wasn't there at the time. I saw the beginnings of this in him. I do know that he went on to become a Berkeley city councilperson. I do know that he had a consulting group. Maybe he had left the university. I know there was a controversy there about trying to get him out of the university. I remember there was something going on, that he was spending too much time on business. Every time I talked to him, I felt it was a lot of hot air: it was nice words, but when I tried to find out the details I never got the details. I could never get to what he really wanted. He was talking very theoretical at that point. Maybe more concrete things came down. I do know that one concrete thing was that he said he could get people into that program, which was very concrete and--

Bonney: City planning?

Fuss: Yes. Into the master's program. I don't know if anyone went in, from the early group, or not. But that was an important opening, because that would be a very critical place for people who were both disabled and interested in physical barriers and social barriers in town to be in. So that was the most positive thing that I, and the only fact, I remember. Aside from that I remember discussions from him talking about the lights on the bridge [San Francisco Bay Bridge] and stop-and-go regulating lights and why, and all sorts of stuff that was not particularly relevant, so I didn't stick around very much when he was talking because I had lots to do [laughs]. I wasn't interested in hearing this kind of stuff about why the mathematics of why that makes bridge [traffic] flow faster. I was willing to take his word that it did [laughs].

Conflicts Between Disabled and Non-Disabled Persons at PDSP, 1971

Bonney: Let me just ask you one more question. You left PDSP around the end of 1971?

Fuss: Yes.

Bonney: During that time period, where there conflicts within PDSP between people with disabilities and people without disabilities?

Fuss: Very much so.

Bonney: Can you describe that?

Fuss: The very simple way was the language. There were the "walkies" and the "crips". It made me uncomfortable. That was one of the reasons for my leaving. First, I didn't want to be a second-class citizen anywhere. Second, I felt like I wasn't particularly welcomed on some of the--like there was resentment toward me, both for my role as being a "walkie" and my role as assistant director.

Bonney: Was the feeling that because you weren't visibly disabled you shouldn't be assistant director?

Fuss: Yes. And fun was made of my illness.

Bonney: So people were aware that you had a disability.

Fuss: Yes.

Bonney: But that didn't really matter?

Fuss: That didn't matter. That was one of the things. It was sort of painful, but expected. I had gone through that in the civil rights movement. It seemed that there was some evolutionary step in which groups turned inward, and anyone who is not self-identified and group-identified as being "the real thing" sort of got pushed to the fringe in a way. At least for a little while. People tend to come out of that. But that certainly was going on. I can remember that from the Black Power movement and recognized it and felt that that was one of the things that was going on. There were jokes and all sorts of things.

Bonney: About you directly or just jokes in general?

Fuss: Jokes in general.

Bonney: About non-disabled people?

Fuss: Yes. And there were nasty comments directed toward me from some people. Not by everybody, by any means, or even by a majority. But the fact that they were there and not jumped on by other people makes them feel bigger than just one or two people saying it. If no one is protesting--

Bonney: So John didn't protest that people were doing this?

Fuss: No, he didn't.

Bonney: Did he know?

Fuss: That's what I'm trying to think--I'm not sure how much he knew. I never felt this from John at all, and I think John's career path showed that that was not at all of interest to him to divide people in that kind of way. That's not what he did.

So that made it somewhat unpleasant, particularly since I was in a very visible leadership position. I also was getting very sick at that time and needed what turned out to be a number of surgeries.

Bonney: [tape interruption] I was asking you, Michael, if you felt that there was a relationship between the problems that began to arise between disabled and non-disabled staff and people at PDSP and the idea of coalition building and bringing in other disability groups. Was PDSP really interested, in that time period, in bringing in other disability groups? You talked a little bit about blind, but what about developmentally disabled or deaf or other kinds.

Fuss: Deaf were on the radar screen. Developmental disabilities people you didn't hear about; you've got to realize the time. We're talking 1971, which was my time frame--the last period I was privy to the inside, and we knew very little about it. It wasn't talked about, so that wasn't on the radar screen at all. Basically the groups thought about were the blind, the deaf, people with less severe physical disabilities. It was the Physically Disabled Students' Program; that's what its name was. Physical disability was the area that was focused on.

More About John Hessler

[Interview 2: December 11, 1997] ##

Bonney: Mike, you wanted to talk a little bit more about John Hessler.

Fuss: Yes, just a little bit more. One of the first things I wanted to add to what I said was that I think one of the really valuable characteristics that John possessed was that he was never an ideologue, nor was he persuaded by particular fads that passed through and were popular. He had his own set of values, and not

only did he have his own set of values but he was also open to change through reasoned argument, observation, and experience. So it wasn't like he was frozen into a position, but he made up his own mind. One of my experiences of John is that we were always talking. We were always talking about problems, possible solutions, arguing about philosophical issues, arguing about politics, discussing politics--I just feel we had a very ongoing dialogue which changed me and changed him. I very much appreciated that quality in John.

The other thing is that John had a stillness at his center; he didn't have a need to fill up space or to talk excessively or to talk at all if he didn't need to. He was just there, and his being there was powerful. When we weren't in a confrontational situation but were talking to other people in the university administration and talking about issues and talking about problems and talking about trying to persuade them to help in particular kinds of ways, John was very personable and very clear and made people feel comfortable. He was very effective in getting people to communicate to him about what the issues and problems were that they saw, which then allowed us to figure out how to address their problems so we could solve their problems so they could solve ours. And he was very effective in creating a collegial way of operating. He carried this on. When he and I talked after this period when he was working in Sacramento after the Department of Rehabilitation, we would be talking about how during the Reagan era there would be orders and laws to make things more difficult for people to get medical care and other kinds of care, and he would talk about how he was ameliorating and saving pieces of programs and trying to pull people together and to pool resources to solve problems. You did ask me about his bureaucratic style, so I did want to do that. The other thing is that John angry was really something to behold [laughter].

Bonney: What would he do?

Fuss: First of all, he had a very deep voice, which I'm sure you remember. Usually he was fairly soft with his voice, but he could bellow [chuckles]. I mean, his voice could shake a room. When he got angry, which was not very often, he really got angry. I just wanted to flesh out a little bit who John was in many kinds of ways.

Bonney: I heard John could also be very dictatorial. If he wanted something, he found a way to get it.

Fuss: Well, that's not dictatorial. His style was straightforward; it wasn't manipulative or sneaky or underhanded or trying to persuade you that it was in your best interest to do what he wanted. He

was very straightforward about it. I wouldn't call it dictatorial; I would call it authoritative.

I think that in those times it was strength of character of the person or people who had to deal with him. He couldn't get away with that with me because I'd stand right up to him. My feeling was that in this program he was the director, and he did have final say. A lot of times my feeling was that it was my job to argue and give alternatives and do research and do all sorts of things and present him with a number of alternatives, a number of ideas, a number of facts, explore them with him, give him my recommendation, and he would make a decision. That was his decision to make; it wasn't mine.

I don't remember disagreeing with him very often. That's also true, but the other part was that the management style that he had at PDSP with me--he was there after I left, so I don't know how it was then--with Larry and myself, it was a very management-team style. We really worked together, talked together, went out and had meals, went out and drank--we did all sorts of things together outside of the office, and talked.

Many of our decisions were consensus decisions which we came to together. A give and take. Even at the time right after the decision was made, if you asked us whose decision it was or who said what or who persuaded who, it would not be clear, because it was not a very clear process. Larry started having some problems, so John and I were doing a lot more of that together. I just felt a fairly seamless interaction with him in terms of all kinds of decisions that were made at PDSP. I felt very involved in all of them, and I didn't experience him in that kind of way. I could see other people doing that. I also feel it was very hard for a number of people who went from being basically roommates at Cowell to John being the head of the Physically Disabled Students' Program. The program determined things about their lives. John, being the head of the program, said, "This is the way we have to do it." Because it wasn't the way we had to do it purely in terms of what we wanted, but in regards to our grant, what we could do in terms of what we could get out of the university administration, and in terms of what we saw as good and possible.

Bonney: Who were the students who had trouble with this?

Fuss: I think everybody at one point or another [laughs].

Relationship With Edward V. Roberts

Bonney: How does Ed Roberts fit into this picture?

Fuss: Well, let's go back a little bit with Ed. In getting the grant and doing a lot of other things, Ed was important. In getting the student classes together--which we talked about last week--Ed was a key person. It was his contacts that enabled us to do that easier. We probably could have done it anyway, but it was just turned over to him. Arleigh Williams was his first contact, and he turned it over to John. John, actually during that first year, was working with Arleigh as an unpaid advisor on the physically disabled at Cal. That was something that Ed set up in a lot of ways, but John nurtured and made real. In terms of getting the money in the first place, Ed told me and various people that he was the one that went to Washington and made contact with a senator who had an arm that was totally useless from World War II, who was a Republican, who was able then to influence the Republicans to vote for this program which was seen as a minorities program--special services and education department--and reserved a certain percentage for the physically disabled. The only person I could see who matched that description was Senator [Robert] Dole.

I'll go back to my personal experiences. My personal experience was that I first got involved as an aide.

Bonney: With Ed, you mean.

Fuss: No, with Scott Sorenson, and then with John. Those were my regular people. I would fill in sometimes with other people. But basically getting two people up in the morning and two people down at night was enough. It was a lot [laughter]. But I occasionally worked for Ed. Ed's room was next to John's room. I worked for Ed on occasion, and I found myself very uncomfortable.

Bonney: Why is that?

Fuss: It took me a while to figure out what the uncomfortableness was. I realized that Ed was very charming, kept people around, started conversations, and was not paying for that time but asking you to help him during that time in which he would bring people in. I started feeling manipulated. I started feeling used by him--in a very charming way. It was not heavy-handed. But it wasn't something I liked. So I stopped working for Ed as an attendant, because that was something I did not like to experience. I think that colored my future interactions with Ed, which I kept to somewhat of a minimum, because my feeling with Ed was that he was

never straightforward when he wanted things. I don't know what that was about, but that was my experience, that he tried to manipulate situations so that what he wanted happened.

Bonney: That brings up an interesting point. The relationship between an attendant and the person who has employed them gets kind of fuzzy, I imagine, at some point, when you're also friends together. Ed sort of overstepped that boundary, I think is what you're saying. He used you or--

Fuss: No, I wouldn't see it that way. Ed presumed that we were friends when we had no relationship of that kind, whereas with both Scott and John we became friends over time. Ed assumed that I was a friend of his--or treated me as if that--from the first time I met him, and presumed on us having a friend's relationship--which we didn't have. As far as I was concerned we had an employer/employee relationship, and I planned my time and had other things to do. I felt John was very clear about that, and with he and I it was somehow clear when we finished the job. If we both felt like doing something together, talking, whatever we did--if one of us had something else to do, we did that. So there was a very clear demarcation between our time working and my time which he wasn't paying for. We were friendly during the time that he was paying my wages also, but it's a different relationship. Ed just presumed that we were friends, and we weren't. I hardly knew the man; I walked in and he just presumed that I wanted to stay and talk with him and be his friend and do this and do that. Friends become friends over time [chuckles].

Bonney: What else about Ed?

Fuss: Well, as I said, I tried to stay away from Ed. One of the incidents that strikes me was at Phil Draper's funeral mass. I don't know if you were there. Hundreds and hundreds and hundreds of people were there. They opened it up for anybody to come up to do a eulogy. After a while it got to be a little bit much for me, so I went for a little break outside, ran into John and a few other people from the old program. I think Herb [Willsmore]. We were just bringing each other up to date. And all of a sudden we notice around the corner is a TV setup, and Ed's being interviewed. I don't even remember who said it, but somebody said, "Where there's a camera, you'll find Ed." [chuckles] I just sort of found it inappropriate; I mean, this was a funeral mass. It was something that he had set up--the interview. It wasn't something like they caught him coming out. It was a set-up interview. He was talking about Phil, but he was talking about other issues and stuff, and my feeling was that this was a time of sadness and grief and not a time to be made use of in that kind of way.

Rolling Quads Fight Back

Bonney: You mentioned earlier that Eleanor Smith, who was a nurse in the Cowell Program just up and left one day.

Fuss: Yes, well, it wasn't quite so simple, but--.

Bonney: You had mentioned to me before we started to tape about a horrible pre-PDSP year. Could you talk a little bit about that?

Fuss: I think I talked a bit about that, because as things started happening, as the direction of the program grew out of the medical model and into the idea that people should live independently; that whatever programs were designed should be, if not controlled, at least heavily influenced by disabled people; and as people in the program at Cowell started wanting to become--and acting as if they were--just like all the other students at Cal--and that means in a variety of ways. There wasn't one way that Cal students were; Cal students were a lot of different ways. People were trying on different ways of being in the world as Cal students. It created lots of tension with Dr. [Henry] Bruyn, who was head of the whole Cowell medical program, and with Lucile Withington as the voc rehab person. I don't know what else was behind that, but there were just a lot more attempts to control people's behavior and to control the direction of the program and to try and divert it from the directions it was going.

I felt really hurt in lots of ways, because I worked very closely with Eleanor from the very first day she got there, and we worked very well together. I learned an immense amount from her about the field of rehabilitation. And it felt to me like she was betraying that trust, that the whole emphasis of rehabilitation is to get people to live as normal a life as possible. There were very personal, nasty arguments with the students and Lucile, and Eleanor was backing Lucile, and Eleanor and I started having arguments. Along about that time we got a new student in the middle of the quarter who as I remember was ex-military and who was brought in there to change people's ideas about authority and the direction that people were going.

Bonney: Do you remember his name?

Fuss: I don't remember his name at all. I do remember about a year or so after that he died in Eleanor's house, because when he left, he left for her house. At least that's what I was told.

Bonney: So this guy was supposed to change the radical Berkeley students into something more acceptable?

Fuss: That's right. He was fairly disruptive during meetings and classes and other sorts of activities. When it was clear that wasn't working and the pressure wasn't working and they started what I was talking about earlier what they did to John and what they did to Donald, and trying to get everyone to straighten up and fly right--whatever that meant--one day he disappeared and Eleanor disappeared, basically. Eleanor took all the stuff, and I did something that I guess was totally illegal--though what she did was illegal--what she did was keep signed scripts from the doctor. And I really figured something was going on, and so I took a bunch of those scripts and put them someplace else, so when she left and took everything, she was gone. I used those for a while, but there was no help.

Bonney: When you say she took everything, what do you mean?

Fuss: Case files. Information on everybody--their medical histories, all the equipment.

Bonney: What kind of equipment?

Fuss: We were buying all sorts of equipment together: urinals, vitamin C--we were doing some stuff with vitamin C, testing urine output for pH, and we were trying to balance it off with cranberry juice, vitamin C and various other things, and she had stacks of that. And all the books and journals for references about that, the logs of where all the medical supplies were gotten--all the different sorts of information. All the information we needed to run a program like that--and she just took it all.

Bonney: And why do you think she took it?

Fuss: She was angry, and this was a way to try and punish and pressure people to do what she wanted and what the hospital administration wanted and what voc rehab wanted. So that period for me was very stressful, because I was not a nurse, not medically trained, and I was taking care of them. Of course, I called the doctor in, and since Eleanor informally resigned, nobody was replacing her.

Bonney: How long did that go on?

Fuss: It felt like months. I don't remember. It felt like months, because responsibility fell very, very heavy in terms of--essentially it felt like people's lives were in my hand, and I wasn't trained for it. This was not my job.

Bonney: How did the students react to this?

Fuss: Some of them were scared. Most of them were--

Bonney: Happy she was gone [laughs].

Fuss: Well, yes and no. I essentially would call Dr. Wong in, and he and I would do rounds, and he'd ask where Eleanor was, and I'd say, "She's not here today. I don't know where she is." I'd order urine tests, I'd order supplies for them, because I had all these scripts--oh, and medicine, because that was really out of line. I'd have him come, and we'd talk about how he was running out of this and running out of that, and this is what she was supposed to do. I kept tabs on everybody. I was doing her job, I was doing my job, and I was going to school full-time and also trying to organize the PDSP.

Bonney: So what was the outcome of all this?

Fuss: The outcome was they gave in and they signed a new voc rehab counselor up there.

Bonney: Do you remember who that was?

Fuss: Ron? A man. I think Ron; I'm not sure. Edna Brean was brought in.

Bonney: As the nurse.

Fuss: As the nurse. Not that she knew much about it at that point either. I gave her a crash course in about a week and a half on everybody, on everything I knew, because I was just really involved with all these other things; I just wanted that off my back. I needed that off my back. It wasn't my job, and I had other things to do. Everybody sort of relaxed about it. It was a clear victory. Did I talk about the threatened sit-in?

Bonney: I don't believe so, no.

Fuss: As things got really close to the point--remember they were going to kick Donald out and John--the Rolling Quads informed the hospital administration that they were going to have a sit-in in their offices. Donald showed them how he was going to do it [laughter]. It was the greatest thing--Donald just sort of collapsed in his chair. It was terrific to watch [laughs]. Ed was organizing media coverage. We called Ed up, and he said he would be able to get media coverage. I was contacting the various groups on campus, which I had lots of contacts in. We were going through Arleigh Williams, and Arleigh let the hospital administration and voc rehab know that he was not taking anybody out of school for non-academic reasons except for violating University of California regulations, which obviously no one there had done. We were working all the channels at the same time,

which I think is a hallmark of how I like to operate, which is applying pressure inside the university, publicity, radical movement, the students themselves. The deadline got closer and closer and closer, and they folded. The understanding that there was that kind of support from the university, from the media, from the student movement, and from themselves, I think just made everyone blossom. The idea that you really could fight city hall and win completely [chuckles].

Bonney: Now when you say they won, what did they win?

Fuss: What did they win? All the threats were withdrawn. They could live their lives the way they wanted within the university regulations and reason. The university took a more active role in helping develop the PDSP. That sounds like winning to me. There was a nurse on there who was very sensitive to their needs, and understanding that they were college students, they were adults, and most of them were older than most college students, and they should live their lives appropriately.

Coalition Building With Blind Organizations

Bonney: Michael, I want to go back to something else we talked about earlier, and that was the blind coalition and the organizing and stuff that went on around that. What I didn't ask you was what was the outcome of that meeting?

Fuss: The outcome was very satisfactory for the first time. There developed a whole bunch of young membership that was very much interested in becoming involved in the disabled movement, with people with other kinds of disabilities. There was a resolution that if I remember right didn't even get to the floor. But it was supported by enough people that there was a group to work with. So the outcome was that David Konkell was a counselor at PDSP and that--I don't know what went on in the future because I wasn't there. But the idea was that this was a start, and that part of David's job was to keep people in contact with each other and help form some alliances between blind and other kinds of disabled on specific issues. That was the outcome, I think. It also brought home to PDSP that first of all the blind were an important component of any kind of thing moving forward, and that they were already organized. There was potential to work with their organization, which there was a lot of negative feeling about because they were very strong and getting special kinds of monies and help for the blind that other people couldn't tap into.

Effects of Civil Rights and Black Liberation Movement on the
Independent Living Movement

Bonney: Also during this time period what effects did the Free Speech Movement and the Vietnam War have on the disabled movement at that point?

Fuss: I think it had several. I wouldn't call it the Free Speech Movement; I think the civil rights movement was really the most important one. For example, the Special Services grant--there was another one to Berkeley which was for black students.

Bonney: To the campus, you mean.

Fuss: To the campus. And so it was another director on campus. And one of the things that the disabled movement was able to do was hook on, so when they [black students] got a percentage of people--there was a percentage at that time, I believe it was a 2 percent rule, and then I think it was raised up to the 4 percent rule while I was there, where 4 percent of total admissions didn't have to meet qualification. So when they demanded and got a certain number out of that 4 percent that they could bring in, we asked for some too, and we would get--I forget what it was--eight or ten slots in the beginning. So we got slots in which people who would not qualify for the University of California in the traditional way, but who we felt were qualified and with our tutoring and counseling and support would be able to graduate and benefit from it. We could bring them in on our say-so.

Bonney: "Minority" in this term then was disabled. They didn't have to be black students or--

Fuss: Right. For us they didn't have to be. But I think that the whole disabled movement in the beginning was very much modeled on the black liberation movement, and that it went through some of the same phases--in the sense of "black power"--get rid of the whites who were working in it, and I think there was a certain--we talked about one of the reasons why I left, which was I felt it was going through this phase. I don't think it went through that as intensely. I think that the whole idea of liberation, of breaking from stereotyped and tradition-based behavior modes--you're this, therefore you can only do that--was the breaking down of that, saying that wasn't right; we don't know what people can accomplish. That led to the counterculture. It had a great deal to do with people with disabilities saying, "Oh, me too." So there was a model; it wasn't like breaking a path that had never been trod before. So there was a model there. I think that it was very helpful.

I think it was also harmful because it was a particular model that one group developed, and they made at times very disastrous mistakes, and the disabled movement I think did the same. One of the things that I feel I had some responsibility for is that in the beginning, much of the energy was harnessed through anger: people's anger being restricted, people's anger being stereotyped, people's anger at architectural barriers, and at being disabled, and it was very easy to tap into. Once there was an environment available that said you don't have to be like that, the anger was very easy to tap into and it created a lot of energy. That's good and bad. I think that it was an easy route to go, and it also followed the black movement, black rage--much of the contemporary political thinking of that time. I still feel bad about bringing--I'm not sure I'm the only one who brought it in.

Bonney: Why do you think it was bad for the movement?

Fuss: I think that anger is a very powerful feeling and that it tends to do several sorts of things. One, I think it blinds you to the grays and makes things black and white, right or wrong. So it pushes you to the extremes. It also gives an impetus to ascribe motivation to anybody who disagrees with anything you say, as being somebody who can't deal with disability--or in the black case, a racist. So constructive criticism is very hard to get through. Also from an ideological point of view, it puts you to the far left. And it's true that over the years that's been the group that's been most politically interested in helping the disabled. But I think that some of that is because of their own agendas and has nothing to do with it; it's just another schtick of saying, "See how society has treated them. Society is bad." And it's isolated the disabled movement, sometimes, from other kinds of allies, because it seems so tied up. I was shocked at the twenty-fifth anniversary and who the politicians were who talked and what they said.

Bonney: The twenty-fifth anniversary?

Fuss: Of the CIL. They were all very far to the left. They were all talking about liberation, and they were all talking about all the movements and staying pure and connected to all the other small groups of movements in the country. It was very interesting to me, and also personally disturbing that I helped create this [laughter] particular attitude and fostered it.

Bonney: Did this come out of the classes?

Fuss: Yes, it came out of the classes, and it also came out of who we talked to and who we saw as our political allies. We certainly

couldn't go to the frat houses and ask them to support us in the sit-in, right? [laughs] You know, there's practical politics and ideological, and I feel that it got a little too focused on the ideological rather than the practical.

Physically Disabled Students' Program Expansion

Bonney: I was going to ask you if there's anything else you wanted to say about this time period. If not, then I want to move on to the development of CIL. We can always come back if you think of something.

Fuss: I want to talk a little about how after we got established and the whole concept was for the severely physically disabled--and if you read our documents from that period, that's who it was for--to expanding the concept. I did advocacy, and one of the people I got voc rehab money was for somebody who was at the university who suffered from severe hypoglycemia and had real weak periods and was disabled, but didn't qualify at that point for any kind of help, either from welfare or whatever. She had tried supporting herself in a job, and her parents had given her some money. She clearly was bright. And so I was her advocate and appeared at the voc rehab and appeared at Aid for the Totally Disabled and got her money.

We started thinking about what we could do with the deaf and talking about interpreters. As soon as the reality of being responsible hit us [laughter]--you know--we just started expanding the concept of who the clientele was, and we did surveys on campus of how many blind kids there were and how many deaf and all of the disabilities that we could survey. We started seeing that the severely disabled were important because they've always been the most left out and it's always been the least easy for them even with the help of family to get to the University of California at Berkeley.

Still it was disproportionate in some sense, the amount of our effort that went to them. But then we started moving out, trying to make it the whole campus and the admissions policy and the ability to have interpreters in class and people helping with tests and stuff. So it was a lot of talking to chairmen of departments and individual professors and people on a one-to-one basis, trying to talk to them about these problems and how to solve them. You've got somebody in your class, and they write very slow. Can they have extra time? Can they dictate and it

gets typed up later? Or you listen to the dictation? I mean, how can we solve this problem?

Because in a university like Berkeley where there's tenure and people are the top of the top, their classrooms are fiefdoms and no regulation is going to do it, as I'm sure you've found out [laughs]. It wasn't something you did once and got into a regulation and it was over with; it was every one, one by one, over and over again every semester.

So it was very exciting, and we started all those programs, and we were mapping out what had to be done and started working on it. It was a very exciting time. We accomplished a lot very quickly, because we became a presence on campus.

Center for Independent Living Evolution

Bonney: Now you said earlier that the Rolling Quads got a sort of twenty-five-cent tax on every student who went to Cal, and some of that money was used to support the "CIL desk" at PDSP to serve some community people. How did CIL evolve from that desk at PDSP to a CIL on its own?

Fuss: The evolution in some ways was very simple. It was very complex, but it was very simple. First, there was a vision of a much larger kind of institution, and we got this much smaller, limited, university program. Then we all did it, but most of it fell into my territory of being outward-facing, which included recruiting, but also included organizing the community and ramping the areas and doing the politics and just working with lots of people who were not students--doing advocacy, et cetera. Then of course, as we knew, the university said, "No, you can't be using so much of your time and effort out there." Like Chuck's time, fixing wheelchairs and picking up people and changing batteries in the middle of the night as they're half drunk in the middle of Telegraph Avenue [laughter]. I don't know if that was still happening in your day [laughter].

We started talking about how to do that and decided that we had to do it with community-based people. And so I made a bunch of phone calls. We decided to have a meeting--the royal "we"--John, Larry, and I [laughter]. We each made up lists of people who we wanted--who we were calling for this meeting and which we wanted to be people from the community and people would take responsibility. Not just anybody, but people who could eventually be a board or something like that. We didn't want it too large

because then it wouldn't function. So we called a meeting. I remember calling Hale and a few other people, and basically what I remember most from what I did was that I sort of stated what I had been doing, stated that the university wasn't happy with this, that we needed some kind of an organization to do this. We gave them some material, and I sort of remember leaving, saying, "Here you go!" [laughter] John stayed. That essentially became a board meeting. I think it was Phil [Draper] who became the first chair of that, if I remember right.

Bonney: Of the board?

Fuss: Yes. I think Larry Biscamp was chosen as the first executive director, which was one of the--to be perfectly frank--I was aghast [laughs].

Bonney: Why was that?

Fuss: At that point I saw him as a very irresponsible type of person; not someone who could really both have vision and do day-to-day work to get there.

Bonney: How did he get elected?

Fuss: I don't know; I wasn't there. I felt that wasn't my purview, that I just sort of, you know--I had been doing this and it needed to be done, and I saw it, and I gave him what I could and would give him whatever assistance they asked for, and that I had other duties.

Bonney: Now they got grant money. Do you know who--

Fuss: Yes. I don't know any of that; I really did remove myself from it. One of the reasons was I felt I was too powerful in terms of personality. I had been around too much in many of these people's lives. We needed people to really come forward and become leaders. We needed somebody who was already in a position in one organization to do all the work or do that in another. Just needed new leadership.

Bonney: Now do you remember Hale's role in establishing CIL?

Fuss: As I said, Hale was there all the time. He wasn't there for the development of the PDSP, but he was there for the development of the CIL and with the PDSP in the beginning, very close to when we first started being on campus--that's when he became in touch with us or we became in touch with him. We had noticed him--I don't remember who made the first move. I think we made the first move; I don't remember who it was who invited him to come for lunch and

talk with us. I talked a lot with Hale; it took me a while to understand him, which I've lost most of at this point. He and I had a lot of conversations. A very bright man. We kept them at PDSP, so we had this extra money, and so we had a way for them to at least have a place and have assistants and secretarial [help] and supplies. We'd provide it, and we could move it through that money out of the twenty-five cents.

Bonney: So PDSP did do clerical work in support of CIL?

Fuss: Right, but it was paid for basically by this slush fund. Soft money, it's called. Soft money, slushes. They both have very bad connotations these days. But soft has a specific meaning, and that's what it was; it was soft money.

Many of the sorts of things I was doing with the ongoing project with the ramping was turned over to them. The one thing I did for them was--I think it was in the second year of their existence--I was asked to do a consulting job with them. What I did was coalition building--the idea being--who were their natural allies? The decision was that basically it was the senior groups. Many of the seniors had some of the very same kind of mobility needs in the city as a whole. So what I did was personally and through a lot of contacts in city government that I had at that point--professionals who were working for the city--I located every group in the city that was doing anything either with the disabled or with citizens who included seniors. And I analyzed each group. I analyzed what they were doing, what they knew and how they felt about working with whites--because most of them were minority--how effective they were. There were people who told me, "Oh, we don't have a problem with people in wheelchairs," who were working with elderly blacks. You just leave them alone [chuckles]. It was a very confidential report, because I talked about personalities of these people--who I could put you in contact with who would be a positive contact, who I could do it with, how to approach them, and that sort of stuff. I just came across that report, a draft of it. I turned it in, and I don't know what happened to it.

Bonney: So you don't know how CIL used it?

Fuss: I don't think they used it, because years later Ed asked me for a copy of it, which I couldn't locate at that point. And it wouldn't have been valuable anyway, because it was a very specific time in which these are the politics, these are the personalities, these are the organizations, and this is what they're doing. It was not anything I wanted to have anybody see but one person over at CIL.

Bonney: Who did you give it to? To Larry Biscamp?

Fuss: I turned it over to Phil.

Bonney: Now Larry Biscamp was the first director of CIL. How did Ed become director?

Fuss: I'm gone. We've reached my limit of personal knowledge and involvement.

Bonney: Did you serve on CIL's board?

Fuss: No, I served on PDSP's board. Just briefly.

Bonney: When was that?

Fuss: In '72, I think.

Bonney: Were you on it for a year?

Fuss: For a year. It was kind of an advisory board.

Bonney: Was this after you had left?

Fuss: Yes. I left at the end of '71. John and I would get together occasionally and talk. The person who replaced me was Donald Lorence. I trained him.

Thoughts on Donald Lorence

Bonney: Did you ever see Donald in the role of director of PDSP?

Fuss: Did I ever see him in it? Yes, occasionally.

Bonney: Did you observe him? What kind of a director was he?

Fuss: I didn't see him enough to really make that kind of judgment. He had good ideas. I don't know how good he was at carrying anything out. I did do one job for him as director. This was years later. I had been a grant writer off and on and doing a variety of other sorts of things like evaluation research and all sorts of stuff. For my grant writing I was hitting 84 percent of my grants.

Bonney: That's good.

Fuss: A star in the area [chuckles]. At one point I was getting more calls than I could work.

He asked me to teach a grant writing class at the university, for the student-initiated, which was different than the 199, then student-initiated classes. So I taught that for a semester or a quarter or whatever it was.

Independent Living Issues

Bonney: Michael, back in the sixties when the independent living movement was sort of evolving and becoming a movement, where did the concept of independent living come from? How did it first get coined, or how was it used, and did it mean the same thing to everybody? Did everybody know what "independent living" meant?

Fuss: Those are very hard questions. If I had taken notes every day or kept a diary, I might be able to answer them. My recollection and my thinking about it is that it had a number of steps. The first step was "out of the hospital." That was the first step. Somehow not living in a hospital--

Bonney: Any hospital.

Fuss: Any hospital. Or nursing home. Because later on I was consultant for a health group that was looking into setting up parts of rest homes for younger people on disability. So I think it had different meanings to different people. I think we need to bring in the cultural milieu now, because I think they sort of went together in some kind of way. We're talking about the PDSP comes into existence in 1970. The work on it and the idea of independent living really started like two years before that, so we're talking about '68. There may have been a few ideas before that, but there weren't very many people at Cowell before that. The Cowell program was growing by leaps and bounds. There is a whole sense in the air that everything is too tied down, that lives are too regulated and predetermined. There must be different ways and more enjoyable and productive ways to live and interact with people, to liberate one's self--

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Fuss: At this point I'm living in a commune, living with a total of seven adults. I'm living with my wife and a number of other people and two kids. People know my home arrangements and are curious, and I've talked about it. There were a bunch of other

communes around, and there are many ways in which people are trying to say, "I'm supposed to live this way, but maybe I don't want to live this way. Maybe I just don't want to go through the university, live in the dorms, graduate, get married, get a job, move to the suburbs and have kids." It's an era of what seems to be limitless possibility in living one's life. I say, apparently, from hindsight.

I think that very importantly you can start seeing in the lives of the people on the Cowell floor, people choosing to live different lives. We had our hippies up there who dropped acid and smoked pot. We had our beer drinkers who used to get sloshed and sing songs and chase each other and yell. We had our political activists--not that all these categories are exclusive. We had people were living much more like "let me get through, get a job, get married, and live in the suburbs." All this was being acted out on a delayed basis up there. It was not ever in the forefront, but it was occurring.

All this contributed mightily to the idea of "they say I can't do this; I'm in a wheelchair. Who says I can't do it? Who knows what I can do? What's in it for them to keep me here? They're getting lots of money at the hospital for keeping us. They got a grant, and they're getting all this money from voc rehab, and they're getting all this money, and they're getting status for having this great program helping cripples. I don't want to be helped; I want to live a life." So people started doing things.

As I said before, people would get stuck when their battery ran out while they were out carousing around one way or another. People started their hair longer, facial hair, hippie-style clothes or other kinds of clothes, going to concerts, and doing all sorts of stuff like the other students and non-students around Berkeley. I think this idea permeated; I mean, this was the start of the women's movement time, this was the start of the gay movement, a culmination in some ways of the civil rights movement, and the start of the black liberation movement.

This was an era of the liberation movements all over the world. Strong anti-colonial feelings. Attacks against any kind of hierarchy, attacks against patriarchy. Being people who were more hemmed in than most people because of their physical disabilities, because of the medical model, and because of society's view of them.

The disabled were very ripe for becoming a liberation type of movement, wanting to define themselves and live a life as they wanted. And to live a life that each wanted to live. So the time

was very critical, I think, in terms of the individuals feeling that and the society around them--Berkeley--being very supportive. The ideas of people in wheelchairs having sit-ins or people in wheelchairs dancing and partying was a gas [chuckles]. That was just obvious, wasn't it? How come we never thought of that before?

I think the evolution started with the idea of almost a timid first step, which is more of a halfway house kind of image--which were also big there. I did get involved with drug rehab programs, and that was a big thing at that point about drug rehab programs. But what was the end point of a group home or a communal home? Even that was limiting. So that lasted a very short time, particularly after the first people went out. And even after Scott Sorenson died alone in his apartment, that didn't seem to slow anything down.

Bonney: What happened with Scott?

Fuss: I don't know how he died. He moved out, he had an apartment, and within six months--Chuck was his attendant at that point--Chuck showed up one morning and he was dead. I think Chuck suspects that it was suicide. I don't know.

Bonney: What effect did that have on the other students who had moved out?

Fuss: Well, he was the first one. Not very many had moved out at that point. As I said, it didn't seem to have much effect. It was talked about some. He was someone who wasn't very central or connected to many people. So all of a sudden people were doing things. Jim Donald goes down to Mexico with an attendant on the Greyhound bus. Ed is basically living independently. John has to move out; he's graduated college. He's living independently. John had already lived independently in France for a year. So John was that kind of role model. I think John coming back from France and his experience there in some way had a great deal to do with getting rid of the halfway house idea.

Independent living at its concept was a negative: not living in a hospital, not living under medical rules, not having to deal with the nurses, not having to deal with doctors on a day-by-day, everyday basis. I think it grew from there to being like everybody else and choosing the way you wanted to live. Some people set up communal houses, had attendants living with them, or had roommates who were disabled and hired an attendant to stay with them, or gave somebody reduced rent to be there at night but wasn't their attendant--was there for emergency purposes. People came up with all sorts of independent living arrangements, which meant that they were responsible for themselves. I think it's a

very powerful, emotional word--living independently. I think to get down to define it absolutely practically, it didn't have one meaning. I think it meant not living in a medical situation. But it could be a gamut of anything.

Bonney: In this time period when all of this was happening and gaining momentum, did you and other people at the time realize that it was a movement? That you were leading a movement?

Fuss: I had hoped so. That was my feeling about it. But that had sort of been a pattern in my life. I would say that the people who worked mostly thought that way. Anybody who lived in Berkeley anyway knew they were at the center of the universe, and anything you did was very important and affected everyone else in the world and they're going to copy you [laughter]. I mean, that's the arrogance and provincialism of Berkeley. Unfortunately, there's some truth to it--or fortunately [laughs].

I think that many other people that came later--when it did become that--that they were just living their life making best decisions and doing what they could day to day, not terribly realizing that they were contributing to a movement, an ideology, a concept, that hadn't existed before.

I think there were a few of us--Hale, Ed, John, Judy Heumann when she came--who were very conscious of that. John and I were very conscious of that because we went to the directors' meetings of special services projects across the country, and there were a few other disabled programs.

We were absolutely shocked and amazed at how unformed they were in the sense of an independence movement. They were still very paternal, mostly, or starting to move away from that somewhat. And we did a lot of work talking about us. The first conference we went to was in Denver, and we drove the van that had been modified for John to drive there. He didn't drive there; it was a little too much, because we drove straight. And then we drove straight back. There were three or four of us besides John.

That was one of the things we showed off. We had actually gotten, I think, about \$12,000 in a grant to modify a car for a disabled person to drive, which was unheard of, shocking, and we had to fight like the devil for it [laughs] both through the university and through Washington. We put on a show of John driving it at Denver.

Bonney: This was about 1970?

Fuss: This was 1970. I think that that was one of the real breakthroughs, because the other people running disabled programs --most of whom as I remember were not disabled--saw a high quad driving a van. I think it just changed dramatically both the government people who were there and the people who were involved in disabled programs about what disabled people are capable of. I believe it also, since we were working with special services people from all over the place, had an effect on many people who ended up in careers in administration at universities and colleges across the country.

Bonney: Do you know if other special services programs allowed disabled in under their 2 percent or 4 percent?

Fuss: I don't know. I do know that for myself, going to this conference was very shocking on one level, because we thought we were amateurs bobbling around UC and treading water there and getting some things done and all that sort of stuff. We went and we just acted like we usually act, and all of a sudden we were on the steering committee. It was because UC really is an elite college, and the administration is an elite administration, and we hadn't realized how much we had learned very fast [chuckles].

Bonney: You're given a level of credibility just from where you come from.

Fuss: Right.

Bonney: And that's still true.

Fuss: And also you learn. If you're any good there, you really learn how to be a leader and how to manage and how to present yourself and ideas and concepts and getting things implemented.

Personal Achievements and the Power of Passion

Bonney: Mike, what are the personal achievements that you are most proud of in your work in this time period?

Fuss: It's very mixed. There are some that I'm very proud of, and they have dark sides [chuckles]. But let me state that I think that I had a great deal to do with providing an ideology--political contacts which the disabled movement as it developed felt connected to other groups and could make alliances, and therefore have much more power and influence than if it was trying to do it by itself. Individuals could feel connected to something much larger than themselves, which allows people to achieve more than

they feel they can. I feel proud that I helped set up a system where people felt that they could live independently, to go out and live full lives. It's very exciting to me that I did that. The one piece that I think I mentioned before, which has no dark side, is the ramping. Kicking that off and getting that moving and helping shepherd that really gives me a thrill. Helping make Berkeley--both the school and the city--an accepting place and seeing all the people in wheelchairs and with other disabilities there gives me a good feeling, that I was involved in that. I was very heavily involved in the beginning and helped shape it.

Bonney: Do you ever go back to PDSP?

Fuss: Yes, occasionally. Not very often.

Bonney: What's your impression now?

Fuss: It's probably been three or four years. The impression I had when I went back was that it had widened the concepts very broadly to learning disabilities and various things along those kinds of lines, which I'm still not comfortable with. I don't quite understand that. But I didn't ask. That was just my take. It was on a day-to-day basis, really working with people, which is very good. It wasn't clear to me that there was an overall vision of where all this fit into people's lives, or of saying that this should be more integrated in the regular counseling. There wasn't vision. It was just a department doing its job, which was great, and it was great to see, but it didn't seem to have a vision as to whether everything that had been learned should now be integrated into the various different parts of the university, so that it would just be assumed that there was counseling at the counseling office--"Oh, I don't have expertise in this; we can work together and I have people who will help me, or so-and-so has expertise in this field. Why don't you go with him? That's your choice," to the student. Or whether it had more of a CIL ideology of a disabled community and was creating institutions and social functions and other things for the disabled community. It wasn't clear to me that there was an overriding vision about its direction. But it was still there, which was exciting [chuckles]. I mean, how many people get involved in a new institution from scratch and it survives that long? It was nice to see, and there were people who were active and interested, et cetera.

Bonney: This has been a wonderful interview. Is there anything else you'd like to say or bring up or clarify or expand on?

Fuss: The only thing that I would like to say is in looking back, I'm talking looking back, so what you're missing from me is my passion. I was really passionate about this. I was really

excited, putting in lots and lots of time, thought about it all the time. I think you got it a little bit there toward the end when we talked about the cultural milieu and all that, but basically this was a very passionate time for me, and for many of the people who were there. We were all operating on a very high level because we passionately believed in what we were doing; we thought it was absolutely right. How to do it exactly, we differed on. But the idea, the concept, the general direction--there was just no question about that.

Bonney: Is that what made it happen, do you think? It was people's passion?

Fuss: Yes, I think so, to some extent. I think that it could have been done differently, and I think the University of California could have, with different people or with us without our passion, developed a very good program. As a program at UC it would have accomplished the same sorts of things. I don't think it would have spread. I don't think you get that kind of almost religious conversion--push--that lots of people had by just doing a job. So I think it inspired lots of people in that kind of way, which spread it. That has its positives and negatives, of course, but it certainly wasn't dispassionate, and if it had been dispassionate, probably someplace else in the country there would have arisen at that time a number of people who were passionate in going after the same sorts of things, and it would have ended up inspiring people all over the country and the world.

Bonney: Thank you very much, Michael. I appreciate it.

Fuss: Thank you. This was very enjoyable.

ADDENDUM MICHAEL FUSS*

In my talks I have been very aware that the events surrounding the founding of the Physically Disabled Student's Program (PDSP) took place almost thirty years ago and I view them through a veil of time and experiences. This has distanced me from the feelings and newness of our creation of the Physically Disabled Student's Program. I didn't know how things would turn out nor was I sure of our success. This distorts my backward view of our astounding accomplishments and puts them in the context of this is the way it had to happen since it did. Every day was an experiment and brought with it the possibility of success or dramatic defeat. All our actions felt significant and we had no real guide nor model to follow. Sometimes I felt, as we all did but rarely verbalized, that we were inadequate and making it up or faking it as we went along.

I was scared, excited, exhilarated and terrified all at the same time. Our basic principles were right but how to apply them was not always self-evident. Mistakes could doom us and there were people just waiting for us to fail.

One other aspect of my oral history, up to this point, is my awareness of my friends, colleagues and students who have died or who haven't been able to participate in this oral history. My feelings of responsibilities toward them has influenced me to attempt to be as objective and inclusive of their points of view as I am capable of being.

One set of experiences that I have described still has an effect on me. I still feel enraged and full of contempt toward Eleanor Smith RN, the rehab nurse put in charge of the floor at Cowell Hospital; Lucille Witherington (I don't remember the spelling of her name), the voc rehab counselor in charge of all the disabled students at Cowell; and Dr. Broun(sic), the Medical Director of Cowell Hospital.

* The perceptions expressed by Mr. Fuss in this addendum, which he wrote after reviewing the interview transcript, are personal views. For other perspectives on these people and this period at the Cowell residence program, see interviews with Cathrine Caulfield, Herb Willsmore, Gerald Belchick, Linda Perotti, Lucile Withington, and Henry Bruyn. --Regional Oral History Office

They directed a campaign of such calculated viciousness toward the disabled students that I have never experienced anything remotely like it during the rest of my life:

They endangered the student's physical health by removing their primary daily health provider, withholding medication, removing medical records and in other unprofessional ways;

They directly played upon the dependency, the fear of losing their one chance at a real life and the self-doubt most people with severe disabilities, especially at that time, have and;

Attacked these severely disabled students with threats of being removed to back wards of county hospital; attempted to have the University of California at Berkeley kick out selected students who were academically successful but identified as leaders; and used confidential psychiatric information in public to humiliate and intimidate students.

They failed and I believe the anger that resulted from this viciousness of the attacks that occurred publicly, privately, in one to one intimidating interviews and in scare tactics directed at students' families was a motivating force driving individual's success and the success of the Physically Disabled Student's Program.

One other person who had an important role to play was Edna Brean(sic), RN. She took over the Cowell project's day to day management after the previous episode, recreated the medical files, instituted a collegial relationship with the PDSP staff, and helped create a successful living program for severely disabled students at the University of California at Berkeley.

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II

Linda Perotti

AN EMPLOYEE PERSPECTIVE ON THE EARLY DAYS OF THE COWELL RESIDENCE PROGRAM,
PHYSICALLY DISABLED STUDENTS' PROGRAM, AND THE CENTER FOR INDEPENDENT LIVING

An Interview Conducted by
Kathy Cowan
in
1998

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INTERVIEW HISTORY--Linda Perotti

Linda Perotti was invited to participate in the Disability Rights and Independent Living Movement Oral History Series in the Regional Oral History Office because of her close involvement with the Cowell Hospital Program and the independent living movement in the early days.

Ms. Perotti worked at the Cowell Hospital Program as an attendant for many of the early participants. She talks about the activities at Cowell Hospital, and recalls her memories of such leaders as John Hessler and Ed Roberts. She worked for the Physically Disabled Students' Program in its earliest days, and was present when the ideas for establishing such a program were discussed.

Later, Ms. Perotti worked at the Center for Independent Living and once again, tells of being there at the early discussions for the need for services for the non-student community. She worked in the Research and Development Demonstration Project under which CIL's unique peer counseling program was developed.

Ms. Perotti warmly recalls her early and ongoing friendship with the family of Ed Roberts. She speaks of her continuing relationship to his mother, Zona Roberts.

The interview took place on January 7 and 15, 1998, in the home of the interviewer. Ms. Perotti has an excellent memory and was able to recall people and events in detail. She heavily edited the transcript, adding many notes and an extra page of text.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Kathy Cowan
Interviewer/Editor

April 2, 1999
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name LINDA MARIE PEROTTI
 Date of birth 12/13/46 Birthplace DETROIT MI
 Father's full name TULLIO ALBERT PEROTTI
 Occupation ~~EXP~~ RETIRED Birthplace DETROIT, MI
 Mother's full name JULIET F. PEROTTI
 Occupation RETIRED Birthplace HARRISBURG PA.
 Your spouse TERRY CLIFFORD BRITT
 Occupation CONSTRUCTION ESTI^{MATOR} Birthplace BERKELEY CA
 Your children JULIA MARIE BRITT
TIANA CAREN BRITT
 Where did you grow up? DETROIT & LOS ANGELES
 Present community CASTRO VALLEY, CA
 Education ① U.C. BERKELEY, 3 YRS. UNDERGRAD. DATA PROCESSING CERT; ② ANTIOCH College = B.A.
 Occupation(s) ① COMMUNITY WORK WITH THE DISABLED STUDENTS MOVEMENT ② GARDENING, ③ SOFTWARE TEST ANALYST.
 Areas of expertise ① ~~6+~~ LANDSCAPE HORTICULTURE
② SOFTWARE DEVELOPMENT - Q.A. CYCLE
 Other interests or activities HIKING, READING, MOVIES, VISITING WITH FRIENDS AND FAMILY
 Organizations in which you are active _____

INTERVIEW WITH LINDA PEROTTI

I EARLY YEARS AT BERKELEY

[Interview 1: January 7, 1998] ##¹

Background, Family, Education

Cowan: Linda, tell me a little bit about your background--where you were born, where you grew up.

Perotti: I was born in Detroit, Michigan, in 1946, in December. I lived in Michigan until about 1960, at which point we, my family--my parents and my sisters and I--moved out to southern California, where my mother's family still lives. That's where we settled. I think I was about fourteen or fifteen, so I got there just in time to finish the last year of junior high and go through four years of high school. I never really liked it much because it was so different from what I expected. It didn't have streets paved with gold like I thought [chuckling]. We didn't get instantly rich when we moved there.

We moved to the San Fernando Valley. I don't know if you're familiar with that, but at the time it was a very homogenous area. Not a lot going on culturally. I met a friend in high school. He was a few years older than me. He went on to the local junior college, but when I graduated high school he encouraged me to apply to UC Berkeley. He said to me, "Do you want to spend the rest of your life in the San Fernando Valley?!" I said, "No." He said, "Well, you better apply to some colleges that aren't around here."

So I applied to Berkeley. I was admitted as a freshman, and I moved up to Berkeley to go to school. I really, really liked it. I loved Berkeley from the time I got there.

¹## This guide indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Cowan: What year was that?

Perotti: That was 1965. It was the year after Mario Savio's Free Speech Movement. It was exactly one year later.

Campus Life, 1965

Cowan: Do you remember the day you got there? What the campus was like?

Perotti: It was a Sunday. It was the Sunday before school started. My mother and my aunt drove me there. We had spent the previous night in San Francisco, at a hotel, and we had gone to Finocchios [a nightclub that featured female impersonators] that night. That was quite an experience. I had never seen anything like that before. I had a lot of fun with my mother and my aunt. And then we drove over to Berkeley, in my aunt's car, and went to the dorm. We carried all my stuff up to the dorm, and I met two of my friends from the San Fernando Valley, two men who were also there--my friend John Cressey had encouraged me to go. He had transferred from the junior college. We had another friend, Bill Chamberlain, who was there. It was his second year, so he was the real veteran. He was happy to see us and showed us around.

I remember my first evening very vividly. That evening, after I got my things into my dorm room in Ida Sproul Hall, we walked across the street to Kip's, which is still there, and had hamburgers, my first Kip's hamburger. That's how I started it all.

Cowan: What was the campus like when you began school?

Perotti: Similar to the way it is now in that on school days it was always bustling, from eight o'clock in the morning till five at night. It was always bustling, people walking around, people going in different directions, coming and going. The fall was a great time. I remember I was confused by the weather for a while. Since I was from the San Fernando Valley, where it was almost always hot or hotter or hottest, and almost always dry. It took me a while to figure out that a beautiful fall day often started with fog in the morning or overcast skies, and then would clear up to a really lovely day.

I remember just walking around a lot. I wasn't used to the hills. I remember people talking about developing "Cal calves" during the first couple of weeks. And the thing I remember most is the Sproul steps, just sitting there and watching people go

by. I also remember the year before I was admitted, the Berkeley students won the dubious award of being in the top ten as the worst dressed college students in the United States [chuckling]. It was a very casual atmosphere, which I liked because I didn't have a lot of money. I had enough money to go to school and live in a dorm, but not much beyond that, so the casual atmosphere was great. I felt really comfortable there and didn't have to have a costly wardrobe.

I really enjoyed the environment. The classes were huge. Looking back on that, I think that was a detriment. But I think a lot of that is the same today, you know.

Cowan: Was there a lot of political activity?

Perotti: Oh, yes. Oh, yes. In Sproul Plaza, or that whole area, there were always tables set up. Now, I haven't been on campus on a school day recently, so I don't know if it's still like this, but there were tables set up all over the place, with different political agendas, usually left-leaning type--like the SDS, Students for a Democratic Society. That was a very, very active organization. I remember a number of women in my dorm were involved in SDS at that time.

I think when I first got there, students were already into having speeches quite frequently in the plaza, on the Sproul steps, because the Free Speech Movement had just started the year before. But then the Vietnam war was really accelerating, and anti-war sentiments became a dominating subject.

One of the really negative things that I remember is so many of the guys I knew were really petrified of being drafted. They didn't want their grades to drop. Some of them, even though they had a student deferment, were called to the draft anyway. Or called to go to their draft board for their examination or something, whatever they called it. A lot of them went to some pretty extreme measures to fail. Not eat for weeks on end so they'd be too skinny, or they'd go in and pretend they were really swishy. You know, just really trying to get out of being drafted and sent to Vietnam.

I remember one of the eeriest sights, when I really became aware of what a political hotbed Berkeley was. I mean, I knew it was already, but to feel it--I lived, as I mentioned, in Sproul Hall, and I lived on the sixth floor. Sproul Hall is on Durant Avenue. The room I lived in was on a side that faced down, overlooked a parking lot. I think it's where that parking structure is now. I think there used to be a big flat parking lot there. And I looked down one night when it was dark, and I

couldn't believe what I saw. There was what turned out to be a SWAT team. They were all cops, just gathering, with shields and helmets and batons. I had never seen anything like that. It was extremely scary. Now if you saw that, you might just shrug and say, "Oh, something's going on." But in 1965, it was a real phenomenon. That's when the police were first beginning to react to the antiwar expressions in an active way.

I don't know what had been going on that night. That was the funny thing about Berkeley. I was not very politically involved. I had friends who were, but I wasn't. So half the time, as things accelerated, they'd be dropping tear gas and I wasn't even sure of what was going on. Or there would be police around, swarming. Or this and that. And you'd say, "Well, what is it that happened today? Why are they here today?" It's such a big place, you didn't always know why they were there. So it was an interesting time.

Brief Introduction to the Residence Program at Cowell Hospital, 1965-1966

Cowan: The Cowell program. Tell me a bit about how you got interested in the students' Residence Program.

Perotti: Well, I first heard about it on a Saturday night during my freshman year. My roommate at the time, of course, was a woman because back in those days only women lived in the women's dorms [smiling] and men lived in the men's dorms. My roommate was Barbara [Karten], with whom I became very good friends--we still keep in contact. It was a Saturday evening, and we weren't really doing much. It was pretty late, and she said, "There's this guy in my architecture class. I've got his address. He's got some papers for me to pick up. Why don't we walk over to his house?" This was up on Dwight Way and Piedmont Avenue, up in that neighborhood. So we walked from the dorms. We walked up there.

That was the thing I liked about Berkeley, too. I mean, I always felt--whether I was right or not [laughing]--that I could safely walk around. We walked everywhere. None of us had cars. None of my roommates had cars. The girl next door was the daughter of the director of "The Magnificent Seven," John Sturgess. She didn't have a car! We didn't have cars, televisions, and certainly not computers. And we didn't have our own phones. So everybody walked everywhere.

We walked up to Eric's house. Eric Dibner, who if you talked to anybody in the disabled movement from those days, they'd know him. We walked up there to his house, and we went in. He said, "Oh, hi. How are you doing?" That was the first time I had ever met him. He gave my roommate, Barbara, the architecture papers, some class papers or whatever they were, and then he said, "You just caught me. I'm on my way to work." We said, "Work? It's eleven-thirty on Saturday night. What kind of work do you have?" [chuckling]

And he said, "Oh, I work up at Cowell Hospital for John Hessler. I'm his attendant." We said, "What? What are you talking about?" He said, "Oh, there's a program up there. Disabled people live up there." He might not even have said "disabled." He might have said "handicapped." I'm not sure. I think handicapped was the terminology of the time. Or he might have said "somebody in a wheelchair." He said, "Yes, I go up there every night, and I help him. I'm his attendant. I help him to get in bed at night." "Oh, okay. Well, see you later, Eric. Too bad you can't stay and enjoy the party." [chuckling] And that's when I first heard about Cowell Hospital and the disabled students living there. That was in '65, '66.

Meeting the Roberts Family, 1968

Perotti: Two years later I moved down to Ward Street right across from Ed Roberts and his family. The Roberts family had moved onto Ward Street before I did. I had some friends at that time who lived there, and I used to go visit them with some other girls from the dorms. We'd all just visit and hang out at their house. That's when the Roberts moved in, so that was '65, '66, '67--they must have moved in around '68 or so, '67 or '68. Yes, it was around that time.

I had met Mark, Ed's younger brother socially at one point. He said, "Oh, I live on Ward Street." I said, "Oh, that's across the street--I know some women who live there." He said, "Oh, who's that?" And I said, "Let me ask you something. Whenever I've been over there, I see somebody riding around on a motorcycle." He said, "Oh, that's me." "I see these other guys, all these guys, coming and going, different age group of guys," I said, "but I see one woman, older woman, a woman, with hair down to here. Who is that woman who lives with all you guys?" He said, "Well, the guys are my brothers and our friends. The woman is our mother." I said, "What?" He said, "Yes." I said, "You mean the one who hops on the motorcycle?" He said, "Yes, I take

her up to school every morning and drop her off." [chuckling] I couldn't believe it. And that's how I first was aware of Zona Roberts.

Cowan: Ed Roberts' mother.

Perotti: Yes. So a few months later, I ended up moving there myself. My friends moved out, and I took their apartment with another friend. In fact, Barbara and I took it. That was the summer of 1968, the year I began my friendship of more than thirty years with the wonderful and amazing Roberts family.

Cowan: You were still in school.

Perotti: Yes. At the time, I was still in school. I lived across the street from Ed. I took that apartment at the end of--in the summer of '68. I had met Mark already, so I kind of had my "in" there, and I went over and said, "Hey, Mark. I'm living across the street now." He introduced me to his mother and Ed.

I met Ed. I'll never forget. Their house was a big, Victorian style, house. He was in the living room--what would be the living room--with the big bay window that faced out onto Ward Street. That was his bedroom. Zona had the back porch ramped, so he'd enter the house in his wheelchair through the back and be wheeled through the kitchen, which was very narrow, one of those old houses from 1910. He'd go through the dining room, which was always stacked with stuff everywhere, and he'd go into the front room, which was both the family room and Ed's bedroom.

So I go over there to meet the rest of Mark's family. Mark introduces me to his mother, who said, "Oh, come on and meet Ed." I go out in the living room, and Ed's lying out on the open iron lung on top of a bedpan. [laughing] That's how he used to do things back in those days! He'd lie out and they'd put a bedpan under him. He was so casual. I said, "Oh, hi, Ed." So here's this guy lying out on his iron lung. He had been in the iron lung. So then they opened it up, and they put this bedpan under him. "Hi, Ed. How are you doing?" He's stark naked and I'm thinking, "This is really weird." It was a very strange experience. But if anybody ever spent much time around Ed--maybe he got a little more modest [laughing]. But that's how I met Ed.

Cowan: What was he like?

Perotti: Oh, he was very friendly. The whole family--they're a very friendly family. Very, very friendly people. And just very unassuming. At the time, Zona was a student at Berkeley herself. Her husband had died a few years earlier. I don't know how she

did it financially. She was always on the edge, but somehow she managed. She did own the house, not outright, but she did. She went back to college. She got a degree from San Mateo Junior College, and she transferred up to Berkeley, where her two oldest sons were. Ed was in a Ph.D. program, and Ron had just graduated. He was in the navy.

So she transferred to Berkeley. She found that house on Ward Street. She leased it, with an option to buy. They don't do that anymore. She ended up buying that house, and that's where the family lived for quite a few years. And that's where they were when I met them.

Cowan: Did that lead to your becoming an attendant?

Perotti: What happened then--I liked Ed--I liked all of them right away. I mean, I already knew Mark. We had a lot of common interests. He was a couple of years younger than me. I really enjoyed their company. Very warm, welcoming family. They always had people coming and going. It was definitely an action spot.

I think it filled a need for me because I had a lot of friends in Berkeley, but they were all students--from other places. Nobody had roots there, so to speak. And even though the Roberts had just moved into Berkeley as a family, it was a family. It wasn't a single sophomore from Minnesota and a freshman studying art from Florida or, you know, a math student from India. It was a family, doing family things. Randy, who was still alive then, was at Berkeley High, and Zona was doing her upper-division work at Berkeley, and Ed was very politically involved already. He taught school. No--he didn't teach school. He was a teacher's assistant. He was in the political science program there [UC Berkeley], so he was a T.A., and he had people coming and going all the time.

II THE RESIDENCE PROGRAM AT UC BERKELEY'S COWELL HOSPITAL

First Impressions

Perotti: It was right at the beginning of summer that I met Ed, and he told me more about the Cowell program.

He said, "You know, you ought to go up there. They need people to do things, like type, laundry." See, at the time, there were only men at Cowell Hospital. There were no women students in the program--this is '68, yes. So the men only had other young men working for them, students, and they were males always. They didn't hire females. Today, it's pretty much of a mixed kind of a thing, the way it works. But then and up through probably at least the mid-seventies anyway, it stayed pretty much like that.

So there was no opportunity for me to be an attendant, but he said, "You ought to go up there. They wouldn't mind if you could get it together somehow, maybe to cook a meal sometime and bring it up, that type of thing." So I went up and I introduced myself. I don't even remember, really, how it happened. I went there somehow. I don't know if I went there with Ed or with his brother or what.

Cowan: Do you remember who you introduced yourself to?

Perotti: No. I have no recollection of it whatsoever. Somehow, Mike Fuss comes to mind. He was very, very active. He was not a disabled person, but he had a lot of savvy and political awareness and knowledge about writing grants. He was very instrumental in that first grant that they got. He comes to mind. I don't know. It was summertime, I wasn't in school. I really didn't have a job, I had saved enough to kind of get by in the summer. Again, I would do things with Mark and Ed during the day. I remember going on campus with them. I might have gone up with them. I

think that's probably what happened, but I don't remember it per se. I really don't.

Cowan: Do you remember what it was like?

Perotti: Oh, yes. It was very quiet. Well, it looked like a hospital. I mean, it looked like a small, kind of quaint hospital because it was an older building, like so many buildings at Berkeley in the sixties. I think it was a wood structure. I'm not sure, but stucco, I think, over wood. It wasn't quite as sterile as most hospitals. You'd walk up these broad steps and then either walk up or take the elevator. I think they were on the third floor. They had a wing on one of the floors. I remember their wing. It was just a few of them at the time. Most of them aren't even alive anymore. There was Larry Langdon, Bill Glenn, Jim Donald, Donovan Harby, I think. I didn't meet John Hessler because he was in France. He had graduated the year before. Ed was the first; John was the second. John had graduated, and gone on to the Sorbonne [University] to study, to get his master's in French, so he wasn't there. But there were maybe only five, maybe five students at the time, maybe four for the summertime. There weren't very many.

It was very quiet, a very quiet atmosphere. It changed a lot. In the next two or three years, it changed incredibly. It was very quiet, and I met different people. I was looking for odd jobs, so I started doing laundry and typing. Some of them were taking classes, so I typed papers and that kind of thing. They'd pay me a certain amount. And I ended up getting paid to type up that grant, that first grant. I had no idea [chuckling] I was typing what could become an historical paper!

Cowan: It was the first grant for what?

Perotti: They got a \$10,000 grant from UC Berkeley through the dean's office of special student services, I think. It was a \$10,000 grant to actually provide services to severely disabled students who had come to the campus.

Cowan: Who was writing the grant?

Perotti: Mike Fuss was real involved with it. I don't even know if Ed was around then or not. The only one I can really remember was the non-disabled person, Mike Fuss. Well, that summer when I was there, there were fewer people than in the fall. In the fall, the new disabled students came in. Don Lorence, who had Susan's job before Susan [O'Hara]. I'm pretty sure it was Don Lorence. He came in that fall.

I always remember him because he came in a manual wheelchair. He had never had an electric wheelchair. He had been disabled all his life. He was a brilliant person. Been disabled all his life. He was there for a couple of weeks, and his electric wheelchair came because you pretty much had to have an electric wheelchair to get around there. The first time he was in his wheelchair, he was so elated he went out in the hall and he just kind of took his joystick and pulled it back like this [demonstrating], on full throttle, which made him just spin around in circles, like this--just spin around and spin around [laughing].

That was another job I had. A lot of people, when they first got there, had push chairs, so I pushed people around on campus there. I did jobs like that. That summer was fairly quiet.

And then Ed said, "You know, there's a woman coming in this fall. You ought to go up there. She's arriving on such-and-such date, in the morning. Go up and introduce yourself. She's going to need an attendant. Maybe you could get a job with her. She'll need a couple of attendants." So that's what I did. I went up that fall. That would have been my fourth year there. That was the year I stopped going to school. That was '68, the fall of '68. And that's when Cathy Caulfield came in.

Staff and Students at Cowell

Cowan: You didn't know her before?

Perotti: No, I did not know her before. There were a number of students admitted that fall--Cathy, Don Lorence, Larry Biscamp, Larry Langdon, Bill I can't remember his last name, Donovan Harby, Jerome Frazee. Those were all the people who were involved in writing that grant. Those were the disabled people I remember from that year.

Cowan: A different grant?

Perotti: No, no. The grant was later on, 1969. On down the line, I typed it up. By that point, they knew I could type, and they asked me to type it up. That was later on because that summer (1968) there was no political organization on that floor whatsoever. It was just a place where severely disabled people lived so that they could go to school. The nurse who was in charge--her name was Eleanor Smith; I remember her very vividly--she called them

"my boys." She was a real great Rehab nurse. She really went the nine yards for everybody on that floor, for all the disabled people, and she really loved working there.

During that next year--now we're in 1968, and you know how politically volatile things were becoming with the Vietnam War going on and all that. That's when the political awareness began hitting on that floor, and that's when I started seeing changes. Mike Fuss was the non-disabled person. He was one of the main attendants there. He had been around for a while. He was very knowledgeable. At that time, I think John Hessler and Ed--I don't remember Ed being around that year. He was living at home in Berkeley that school year. So that's why I think Mike really became instrumental in kind of guiding people and saying, "You could be doing this and that," in regards to getting grant money.

Cowan: So there was a real shift between the summer and the fall.

Perotti: Yes, definitely. Things completely changed that year. The reason I brought up Eleanor Smith's name is that she didn't like the way things were going. As there were more students there, it wasn't just the four or five of them. Now I think it was seven or eight. I think they felt a little more powerful and stronger.

And they were pretty unusual people. They were really pioneers because there weren't many people, that severely disabled, going out and living on their own and trying to get a degree and all of that. They were becoming a little more independent. There was a lot more late-night partying and drugs, people smoking pot--nothing serious but just, you know, people having a good time. A little drinking, a little sex. This was mind-boggling, I think, to the old-guard nurses who were around at the time.

Cowan: And Eleanor in particular?

Perotti: Well, yes. I don't even think she minded all that, because "boys will be boys," you know. But when they started getting politically active and making demands on the hospital staff--I don't know if they had curfews. I don't even remember what the demands were, but some kind of demands, whatever they were. And they were treated--I think they were treated very nicely. I never observed any ill treatment. I think it was just in keeping with the times. The students were making demands of the administration and the government, and the disabled students were making their own demands and feeling their own muscle and then looking around at what other kinds of things, like grants to write so they could get organized and become more autonomous.

As a group, they were getting organized. That's the thing. Getting organized. Eleanor Smith did not like this. She did not like this at all. I think the sex, the alcohol and the drugs, you know, in moderation, she could have lived with that. But-- I'm just guessing--I know she didn't like the political activity because she gave them an ultimatum and said, "You guys have to get back on track here. Do what you came here for, to get an education." Of course, from my point of view, I thought [laughing] they were getting a great education! Better than anything you would learn in a rest home. She said, "I can't work under this--you guys have to figure out what you want to do. I can't work under this kind of situation here."

Edna Brean Replaces Eleanor Smith

Cowan: Did she quit?

Perotti: Yes. Opened the way for Edna Brean. Edna Brean, who I'm sure is being interviewed, too--worked as a nurse on one of the floors below. She was a nurse, lived in Berkeley. She told me this personally--"Linda, when I heard there was an opening on that floor, I knew," she said, "I knew already that's where the action was. When I heard there was an opening, I jumped on it! I leapt for it! I said, 'Take me!'" [chuckling] And she--BAM! She went up there in a flash. She was great. She was really great. I mean, Eleanor was great, too. They were both great. But as the time changed, it became difficult for some people, and Edna was more amenable to the changes in the political atmosphere.

Eleanor was terrific. She had a lot of knowledge, and she shared it with everybody. She was great. She was very kind, really had the interest of making sure that everybody stayed in good health, because being so disabled can be precarious, with catheters and not being able to feel what's going on. It can be very precarious, and she really made that an issue. She was very knowledgeable in that field. I don't know if she specialized in that or what, but she was very, very good in what she did.

Cowan: But the independence, the shift to more independent living was-- she just couldn't cope with it?

Perotti: Right, yes. I think she just wanted them to be the way they had been the past few years. It changed. I didn't see too much of the way it had been, but I know that in one year it went from a quiet place where there were maybe five guys sitting around passively attending the university to seven or eight, and a

woman. I don't think she minded that. I think she welcomed it. But now they're talking politics and how could they get involved, and become more pro-active.

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Perotti: The thing that was bothering Eleanor Smith, I think, was that the students were becoming more like the students outside of Cowell Hospital. They were demanding their rights, and that was something--for whatever reason--I don't know why--I never was close enough to her to understand why, but that was something she just was not comfortable with. And so she gave an ultimatum that they would have to stop that or she'd quit, and they said, "We're on a roll here." [chuckling] In fact, they called themselves the Rolling Quads at one point. She did quit, and then that's when Edna Brean came in.

Cowan: The fall of '68.

Perotti: It wasn't the fall of '68. I think it was more toward the spring of '69.

Cowan: So Eleanor stayed through the fall?

Perotti: Yes, when the new students came in the fall, and I think it was toward the end of that year, which would have been my senior year, that things were really beginning to accelerate with the students, and they were getting more and more organized. It didn't just all change overnight, as things usually don't. And then Edna came on. She was very supportive where Eleanor had not been. She came in just very enthusiastic.

So I really took it upon myself to orient her to the floor. I showed her all around the wing there, showed her where all the supplies were kept and really tried to help her in any way to get comfortable.

Cowan: But you hadn't become an attendant.

Perotti: Oh, I was an attendant that year, yes, yes.

Cowan: Was this before Cathy came?

Perotti: No. I started working there in the summer of '68. I was not an attendant. And then in the fall of '68, Cathy came, and that's when I became an attendant. So I worked there that whole year. I, and two other female friends of mine, became her attendants. One of us had mornings, one had evenings, and one had weekends.

Becoming an Attendant, 1968

Cowan: Well, how did that happen when you met Cathy?

Perotti: In September of 1968, I went to the Cowell Hospital, to that wing, on the morning that Cathy was expected, and I introduced myself. I remember that she was there with her parents. Her father was in the military at the time. She was from a military family. I said, "My name is Linda Perotti. I'm a student here at Berkeley. I understand you may need an attendant. You know, if you're interested in hiring me, I could provide those services for you" blah-blah. And we talked. She hired me on the spot, and I said, "Oh, by the way, I have two friends who need jobs, too." [chuckling] She hired them on the spot. She was great. She was terrific to work for. She was really great.

Cowan: Did you know how to be an attendant?

Perotti: Well, you know, it's interesting. When I was fifteen, my mother had a baby. My little sister was born. And I spent a lot of time taking care of her. Not that it's the same thing, but basically, you know, you do need to be able to help bathe and just, you know, dress and undress, so in certain ways it's not like taking care of a little tiny baby but more for somebody who doesn't have the ability to move themselves in all the ways they want to move. A lot of that helped, just in terms of being patient and moving people around without hurting them.

Cowan: Did you have any training at all?

Perotti: None of the attendants there did. Everybody who came on were just students at Berkeley.

Cowan: Did Cathy tell you what to do?

Perotti: Oh, yes. She told me. I had to learn how to change a catheter. I had never even seen one before, a urinary catheter. She was very explicit. She would lie on the bed, and she would explain very explicitly how to do that, how to open the new packages and blow up the balloons. I can't remember it all now; it was thirty years ago. But she was very instructive. That's how everybody learned around there. It was from the people they worked for. Because you can imagine, these are people--pretty smart people; managed to get into Berkeley; pretty independent people; broke the mold--and so they were very good at telling attendants how to take care of them. Generally speaking, they were very articulate.

Rolling Quads, Beginnings of Political Activity

Cowan: Was that when a lot of political activity was developing?

Perotti: Oh, yes.

Cowan: The group you referred to, the Rolling Quads. Tell me something about them.

Perotti: Well, this was the group at Berkeley, the group of students who lived in that wing, the names that I mentioned earlier. Larry Langdon, Jim Donald, Cathy Caulfield, Bill Glenn, Jerome Frazee, Don Harby, and Ed Roberts, who was living off campus. As they got more identifying themselves with their own little political movement, getting organized, they called themselves the Rolling Quads. I don't even know where it came from. Maybe one evening somebody said, "Oh, you know, let's call ourselves the Rolling Quads." It was never really official, but I think it was something to identify with. Because at that time, they were all quadriplegics; everybody on the floor was a quadriplegic. Most of them were spinal cord injury or, in the case of Donald Lorence, he was born with a congenital disability which made him a quadriplegic, so that's where the "Quads" came in. And "Rolling," of course, has to do with the wheelchairs. Rolling Stones, Rolling Quads [chuckling] and all that kind of stuff! It all fit very nicely.

Cowan: Did they have meetings?

Perotti: I don't remember per se, but I remember by the time Edna got there, there was a big room, one of the big rooms--I think it might have been Ed's room where he had his iron lung. He wasn't living there that year. But Edna had gotten this big, huge, black enamel round table in there, so they would come in and eat together in the evening, instead of just five or six eating in their own rooms, like it had been that summer, or maybe occasionally meeting out at the nurses' center to eat. They were now eating together every evening. That was a time when, like any family, they came together and there was a lot of exchanges of ideas. I don't remember any official organization where they got together and had meetings.

Cowan: Were you there when they ate?

Perotti: Oh, yes. Very often I was there, yes. Many times. Oh, I remember that table. In fact, I heard recently--somebody still has it. I can't remember where. But yes, there were many times I was there. I enjoyed being up there. It was fun--I liked the

people there. I admired them tremendously because I really could see they were doing something special, not even in the political organization, which was coming slowly and was not a big deal at the time, but just in the fact that they were there.

They had broken the mold. Some of them had come from convalescent homes. Others had come from, like Donald Lorence, a real sheltered home, where he had rarely been out by himself in his life. And here he is at Berkeley. And other people, like Cathy Caulfield, who had broken her neck at fourteen, and what she must have gone through from the time she was fourteen--she was only about nineteen at the time--to have gotten herself mentally adjusted so well that she could come to Berkeley and cope and do it.

Cowan: Were you aware that they were breaking a mold?

Perotti: I was aware that they were special, yes. I did think of them as special people. There was a time in Berkeley during the late sixties and early seventies, and I've heard Zona say this and I've heard Edna Brean say this, that if you heard an electric wheelchair, you'd spin around to see who it was because you knew you'd know the person. There were so few people at UCB in wheelchairs at the time. The electric wheelchair has a very distinctive sound, no matter what brand it is.

I left Berkeley for a while, and when I went back and worked at CIL [Center for Independent Living] in the mid-seventies, there were hundreds of disabled people in Berkeley in wheelchairs. I noticed it at CIL because I worked with disabled people all the time. They were no longer just students; they were people, residents of the community, of the greater Bay Area.

But the disabled people I was encountering during the mid-seventies, then, were the more average people who happened to be disabled. That's when I saw the difference. I said, "Wow!" They were more your everyday person who back in '65 would never have found their way to being a student at UC Berkeley.

Cowan: So that's when you were really aware of how much a change had happened.

Perotti: Yes.

Attendant Duties and Odd Jobs

Cowan: But back to '68, when all of this was beginning to evolve, did you have other duties? You mentioned laundry and cooking.

Perotti: Well, when Cathy came, then I became an attendant and I backed away from the other stuff because I was a student. For a while I was a student there. And I was pretty busy. So I just was her attendant, and I didn't do the other stuff as much. Sometimes I'd still cook, like on Friday nights, if I had time, I'd cook something. I'd pool money together--They'd give me money, and I'd go make a big pot of spaghetti someplace. I'd have to have people help me carry it in and stuff.

There were no cooking facilities. It would have to be something like a big pot of chili or a big pot of spaghetti, something that you could carry there. And they would love it, of course, you know, a home-cooked meal. So sometimes I'd do that. But really, by that point I was primarily Cathy's attendant.

I had a boyfriend during that year, and he was somebody else's attendant. I don't remember whose attendant he was. I spent a lot of time up there because a lot of times I'd just go up with him, just to keep him company, and visit with people. So in a lot of ways, at a certain point I was socializing there. I had the morning shift. Every morning I'd go up and help Cathy get dressed and get ready for school.

So those were my official duties: helping her get dressed, helping her to bathe--they had a shower room where they'd go. Just different things like that. I was still doing odd typing jobs. People really prevailed upon me because I hated typing, but I would still do the odd typing jobs. And errands, you know, for people sometimes, if they couldn't get to the bank and they had to make a deposit, before the days [chuckling] of automatic deposits and stuff.

Cowan: How were you paid for all of this?

Perotti: By check.

Cowan: From?

Perotti: Oh, the individual. The way it worked was that all the individuals there were getting money from the Department of Rehabilitation. The DR (everybody called it) paid for their tuition and gave them money. I don't know how they paid for their books; somehow gave them money for books and tuition. The

DR paid the hospital directly. And then gave them a specified allotment every month for attendants. And that's how they would pay us, was out of that monthly allotment.

Cowan: Was everybody paid about the same?

Perotti: Pretty much. I think it was a pretty even kind of a thing. Everybody kind of paid a standard hourly rate. The difference was the person who would pay you and round up the time [chuckling]. There are little itty bits of pieces of time. You'd go on for maybe two hours and fifteen minutes at night, maybe an hour and half in the morning, so the difference was working for the person who rounded it up to two hours, as opposed to the person who paid you by the minute [smiling]. So that was the big difference.

Cowan: Were you able to live on that?

Perotti: When I was a student, no. I also had grant money, because I had to pay tuition. When I was a student, no, I couldn't live on that. It was during that senior year that I dropped out of school. Then it was enough to get by on. I lived very frugally, and I could get by on it. That and food stamps.

Cowan: Did you see yourselves as a group? Or were you just there as individuals?

Perotti: Well, to me, because I was one of the very few women around--I was the only woman, really, working there at first. Then, when Cathy came in and I introduced her to my two female friends and then there were three of us there. They were friends of mine, so I already had a social rapport with them, and we actually became friends with Cathy. She fit right in.

I didn't see myself as part of an attendant group because the rest were guys, and they worked for the guys, and my two friends and I worked for Cathy, "the woman." So it wasn't really part of any kind of a group thing. To me, I didn't even see them as being really that political. If it hadn't been for Eleanor Smith making such a big deal [of] protesting, their protesting, I probably wouldn't have even realized that things had changed that much.

To me, it was an interesting place to be. I was not a real politically involved person. Somebody more politically involved than myself, they were out doing the real political involvement stuff, on a much broader scale, fighting against the war and organizing marches and all. But this was really good for me because it suited my level of political interest or awareness.

And it was enough activity and action that kept me interested, but not so much that it turned me off.

Services Issues for Disabled Students

Cowan: Who did you see as the leaders, then, among that group?

Perotti: When John Hessler came back in the fall of 1969--he definitely became a leader. Ed went to teach at UC Riverside for a year. See, I can't remember when Ed came back. But at a certain point, Ed came back. Of course, he was definitely a leader. So they were the two most dominant figures. During that year that I was there, the first year, when neither of them were around there wasn't so much of a real [leader]. I really saw Mike Fuss as the one who was kind of the instigator in terms of the idea man, you know, knowing about grants. I don't even remember any conversations, but somehow he conveyed the idea that, hey, you know, you've got some real issues here. Ironically Mike Fuss was not disabled. He was an attendant.

The things that they were interested in were services for their wheelchairs. They all had electric wheelchairs. Well, that means more problems, more complex problems. How do you get a wheelchair fixed in 1968? How do you find a qualified attendant? I hate to use the word "qualified" but by their standards qualified, somebody who was reliable and not flaky and wouldn't steal from them or hurt them in any way. I mean, you're very vulnerable when you're lying in bed and you've got some stranger in your room.

So those were the two big issues at the time, getting their wheelchairs fixed and attendants.

Cowan: Not political yet.

Perotti: No. See, that's why it's astounding to think that Eleanor was sensing--I think she really sensed the bigger thing coming on. I think she was smart to remove herself. I think it was a very wise move because I think she would have tried to slow them down and hinder them, where[as] Edna just kind of let them do their thing and was very encouraging.

Cowan: Put the time period in my mind. You're talking about the fall of '68 to the spring of '69. That's when Eleanor quit.

Perotti: Yes, during that year. I don't remember when. In the fall of '69 things began to get political because the students began raising issues with the Department of Rehab. DR wanted to control certain aspects of their lives. For example, the majors they chose. The students wanted more autonomy and certainly wanted to chose their own majors.

John Hessler came back. When they wrote that first grant--I wish I knew what year it was--somehow in 1969 or '70 rings a bell. By this point, I was traveling a lot. And this was another reason I loved working for the disabled people there because I could work for them, save money, live frugally, save money, and go travel. Come back to Berkeley, find a place to stay, and get a job again, and get work, like that. I would work until I saved money, and travel.

But I remember that John--It must have been 1970--had gotten a \$10,000 grant. By that time, he was no longer qualified to live at Cowell Hospital. I think when he came back from the Sorbonne, he went back to Cowell Hospital, got to know all the new people there, and they let him stay there until he could find a place.

Ah! Issue number three comes up. Finding a place! How do you find a place when you're disabled and you can't even get into a lot of them? And number four, finding an accessible place.

III BEGINNINGS OF THE PHYSICALLY DISABLED STUDENTS' PROGRAM

John Hessler's Role

Cowan: Well, before we get to that, how about just a little more about what John was like when he came back? Did he seem to establish himself as a leader?

Perotti: John Hessler was a very formidable person. I mean, he came into a room like this [demonstrating]. He had a presence about him. Ed did, too. They both did. But in different ways. John was a bigger person, physically. He just had a way, almost an aristocratic bearing. He came from a middle-class family in Antioch, a working-class family. I met his parents. They're very nice, down-home kind of people. But he had a mannerism about him that was almost regal. He could also be very arrogant and very irritating at times. So I think he was just that kind of guy.

He had graduated from Berkeley, he was the number two guy to go to Cowell, he had gone to France. And now that I think about it, I don't even think he ever actually went to school at the Sorbonne. After he got there, he found out it was inaccessible. He stayed there that year, though. I don't remember exactly what happened. I just remember that little detail.

Early PDSP Staff

Cowan: Do you think that it was John's arrival or reappearance that began to change things?

[Perotti: I think John was the one who was in the best position to assume a leadership role. Ed was gone that year (1969-70) teaching at UC Riverside. John had graduated from UCB, and had the time to

continue spearheading the movement. The other disabled people involved at the time were still in college. The first proposal that the group Rolling Quads put together was submitted to the federal government and was denied. So at this time they were reworking their proposal with the intention of re-submitting it. So there was a lot of research and organizational work that had to be done. John, who was living in his own apartment on Haste Street a few blocks from the campus, was in the perfect position for the leadership role, and to keep the movement growing. Even though Ed was not in Berkeley at the time, he and John were extremely close, both socially and politically. This allowed for them to continue communicating about the politics and changing tide of the disabled movement while Ed was away. So I think that even though John took over the leadership for that period of time, Ed's agenda was clearly represented in what was going on. And between the two, Ed and John were a combined force that could not be ignored, either by the Department of Rehabilitation or the UCB administration.

So, as they were planning the second grant and their determination was stronger than ever, roles began to be defined. Roles that eventually became official "job positions" at the Disabled Students' Program, which is what they were finally successful at financing. I remember Chuck Grimes, a non-disabled person who worked at the Cowell Hospital Residence program. He was a graduate student at Cal majoring in art. He worked as an attendant. He was also quite mechanical, and he helped out with repairs on people's wheelchairs. As he got better and better at repairing wheelchairs, he became known in the disabled community as someone who might fix a broken chair. He was hired as the first wheelchair repair person when the Disabled Students' Program started up.

And then I remember this guy--Bill McGregor. Actually he came a little later, during the beginning of the Center for Independent Living days. He was another non-disabled person who worked as an attendant. When the first grant money came, the seed money for CIL, they needed a bookkeeper. So they asked Bill to be the bookkeeper. He really didn't know anything about bookkeeping, but he had a checking account and knew how to balance a checkbook, so that seemed like grounds for becoming the first CIL bookkeeper.

Don't forget, it wasn't all that easy to find people willing to work. Socially, disabled people were still considered an

oddity at that time. We worked for dirt-cheap wages. We worked odd hours. You couldn't get a professional bookkeeper!]²

And that's how they started building. And the focal point was out of John's apartment.

Cowan: Is this Rolling Quads?

Perotti: Yes, they were still pretty much the Rolling Quads at that point.

Cowan: And they're meeting at Cowell and at John's apartment?

Perotti: Yes. I think when he came back in the fall of '69, that he went back to Cowell Hospital. I think he was just there long enough to figure out where he was going to go. It was a good program there. They didn't just say to him, "You're not a student here anymore." They gave him time to make his move. It was very hard for disabled people in wheelchairs to find places at that time because Berkeley is an old city. You have to have doorways that are wide enough; you have to have elevators and ramps and all kinds of things. So he found an apartment in a modern building on Haste Street.

I wasn't in Berkeley when he got that place, but when I came back, I couldn't believe it, the first time I went over there. It was incredible. The hubbub. People coming and going and stuff going on; it was like a little office. In one year, things had changed a lot.

Cowan: It had become a political action group?

Perotti: Well, at that point, you see, the Disabled Students' Program was just starting. It was under the Dean's Office, Dean of Special Services. Then they actually established an office under Dean Arleigh Williams, I believe.

Cowan: An office for disabled student services.

Perotti: Yes.

Cowan: That they had gotten the grant for.

Perotti: Right. Because then they actually set up an office, and that's when John became the director of the program, and Zona was hired as a counselor. She had graduated from Berkeley. She had

²Bracketed section was added by the interviewee during her review of the transcript.

finished her teaching degree there, the fifth year, as a teacher and with a teaching degree, but she decided she didn't want to teach. Timing was perfect. They needed somebody who could provide counseling services, and she, of course, had been with Ed for the past ten years, and his severe disability, and she knew a lot. He had become independent, so she really understood a lot of what was going on. Plus she had good counseling skills, anyway.

And they hired her. And they hired Chuck Grimes to be their wheelchair repair person. I think that's how they started. Then they hired a secretary. So four people opened up that office. And that's--what they were providing there were the services I've mentioned to you, plus counseling.

Cowan: How about Cathy? Was she still at Cowell?

Perotti: Yes, she was still at Cowell.

Cowan: Who else was still at Cowell?

Perotti: Well, most of the people from the previous year [1968/69] stayed on the next year. They were all still trying to get their degrees, many of whom did. And then certain people, like Donovan Harby and Jerome Frazee--they had been there longer. They got their degrees, and when they did, then they moved out into their own apartment.

Cowan: Susan Sygall?

Perotti: She came later.

Cowan: Jim Donald?

Perotti: Oh, yes! Jim Donald! That's the person! He was there. He was there in the beginning. That was another name. Jim Donald was there that first year when I was there. He graduated, oh, around '69 or '70. I can't give you the exact year, but it was sometime around there. Maybe '68. He went up to UC Davis to go to law school. He got his law degree. He was a real sharp guy. I remember him being involved also in this. But he had his own ambitions. He graduated, and he left. That's why I think John was the natural; the others were still working on their degrees, and they were still there, living at Cowell Hospital, and here John was. He had finished his degree. He was the perfect candidate for that job.

More on John Hessler

Cowan: How did people take to him as a leader? Was he a natural?

Perotti: I think he was a really good person to put in that job because he knew how to speak to the bureaucrats at the university, you know, to the officials. I should say the officials at the university. So he was very good. He had a lot of savoir faire, so he could really speak to the people there and be effective and not turn them off. He told me this story--he had just graduated high school. He was about six foot four, a big football player, a big athletic guy, and very competent. Pretty arrogant, even then, back in those days. And he was on a diving board, diving into a pool. He was just feeling fantastic because he had graduated high school. And he took his dive, and before that he yelled out, "I am God!" And he took his leap for his dive, and somebody called his name, and he turned his head, and he broke his neck.

And then he ended up living in a convalescent home. I mean, again, his parents were working-class people. As far as I know, they both had jobs. They couldn't take care of him. This was in the early sixties. He was in a convalescent home.

Cowan: You were talking of his leadership.

Perotti: Yes. Somebody at the convalescent home brought him a newspaper article about Ed being admitted to Berkeley and being a student there and living there and how disabled he was, and the nurse said to him, "If he can do it, you can do it. I don't know this guy, but I know you're as smart as he is." John was at the ripe old age of nineteen, looking at the rest of his life in a convalescent home. Seriously. And that's the point I was trying to make, that he knew from experience what it was like to be shut away, to be part of the lost cause. At one point, he's at the peak: graduated from high school, football player, the world is in front of him. The next thing, he's living for the rest of his life in a convalescent home in Antioch, California. The high point of his week: when his parents come and visit him and bring him a cake or something.

Cowan: So he was the perfect person.

Perotti: Yes. That's what I was trying to say in terms of leadership. He had to even borrow whatever it was, the fifteen dollars or the twenty-five dollars that they charged back in those days for your application fee.

PDSP Services

[Interview 2: January 15, 1998] ##

- Cowan: Linda, we were talking about students' services, but before we get back to that, you said a couple of the big issues at Cowell were finding wheelchair repair and finding attendants.
- Perotti: Basically, it was all word-of-mouth. Finding attendants was word-of-mouth. When a new person would come in--that's when they'd be in need the most because they'd be moving to Berkeley from some other place, so they generally wouldn't know people around. When Cathy Caulfield moved to Cowell Hospital, for example, Ed Roberts said, "Hey, there's a woman coming. There are no women attendants up there. She's going to be arriving on such-and-such date. Why don't you go introduce yourself if you'd like a job?" And "Do you know anybody else?" So that was the kind of thing.
- Cowan: No attendant referral service yet.
- Perotti: No, none whatsoever. I introduced myself, and then I introduced her to my friends. And generally people usually work for more than one person. That year I only worked for her because she was the only female there.
- Cowan: Do you recall when attendants services referral began?
- Perotti: The Disabled Students' Program. That's when information became organized and there was a repository. But up until then, it was just strictly word-of-mouth.
- Cowan: And wheelchair repair?
- Perotti: It was at the Disabled Students' Program also. Once the Disabled Students' Program was established through the dean of the student services office at UC. Chuck Grimes was hired as the first wheelchair mechanic. I think he was friends with Mike Fuss. I'm not sure. I'm pretty sure that's how it was, though. So he came up there. I happened to be there the day he came up, looking. He said, "Oh, I heard that people live up here and they might need some help. I'm looking for work." I said, "Oh, yeah, okay. Well, so-and-so is in his room; why don't you go speak to him? He can tell you who's needing help right now." That type of thing. And that's how it started. That was just the beginning of the transition from what we would call a push wheelchair to a mechanized wheelchair. The push wheelchairs didn't require much repair. The mechanized chairs all came from Everett & Jennings.

I don't know if they'd send somebody out or they'd come and collect it and give you a loaner. Often, the turnaround could take a couple of days or a week or two, and if you had classes, that wasn't good enough. It was like being without a car at that point. So that's why people like Chuck would try to help out a little bit here and there.

Cowan: It wasn't official yet.

Perotti: No.

Access Issues and Support Services When Students Left Cowell

Cowan: When people started moving out and looking for their own apartments, how did they find accessible apartments?

Perotti: They would just go out and look around, just physically go out and look, in their wheelchairs, and try things out. John Hessler--the way I remember it--was the first one to move out from Cowell Hospital. Ed was in and out. By that time, his mother had moved to Berkeley, and she had an accessible house. She had it ramped and everything. So he had his own room there that was always his room, and it was real close to the campus. It was just about a half a mile from the campus. So John was really the first one to go out and look for a place.

Cowan: Did he go alone?

Perotti: He probably had somebody with him because you never know. Maybe you get there and everything is accessible except you can't open the door, so I don't think they ever went looking by themselves. I don't think the disabled students at that time would look alone. They usually would have somebody with them, unless they were doing some serendipitous trotting about or something [chuckling].

Cowan: I actually meant did he move in alone, or did he move in with a roommate?

Perotti: Oh. I think he initially moved in alone. I'm pretty sure that he started living there by himself, and then at a certain point Herb Willsmore moved in with him.

Cowan: What were the problems that they faced in an apartment by themselves?

Perotti: Well, number one, often it was getting in and out. Mostly they would end up in modern apartment buildings because if you're in a wheelchair, only the modern buildings have doorways wide enough to get in and out, or have elevators. You know, you need to have elevators, especially in a hilly place like Berkeley. The older homes are often inaccessible because doorways are too narrow, or there are two or three steps going up that need to be ramped. That could be overcome, but it was other things inside the house. Rooms would be smaller, tight hallways. So the modern apartment buildings were often the easiest to adapt for wheelchairs.

If you went to somebody's house or apartment building, you would get off the elevator and you could just look down the hall for the doorknob with the adaptive device on it. You'd say, "Ah, that must be so-and-so's apartment."

Cowan: What do you mean by adaptive device?

Perotti: It's almost like a rubber lever that would fit onto the doorknob. A quad--John was a quad; Herb was a quad; Cathy--many of these people were quadriplegics, meaning they didn't have the use of their arms or fingers. The natural position of their hands was that they were kind of in a relaxed fist. They could turn their wrists and move their hands around, but they couldn't use their fingers to grasp objects. So the doorknob becomes very difficult. They could get the key in by kind of sticking the key in here [demonstrating] and going like that, and then just kind of hit and push at the same time on the door.

Cowan: The key between their fingers?

Perotti: They'd get the key out. They'd have it on something; stick it in between their fingers, like this and shove it into the lock and turn it. Then there's the doorknob to deal with. One thing I found when going around with disabled people, people in wheelchairs specifically--your pace is slower [chuckling], much slower. Yes, just in terms of getting from A to B.

Cowan: Was the rubber doorknob something that you could buy at a store?

Perotti: There was that store on Shattuck. I think they closed up. There was a store that sold all kinds of prosthetic devices. They had a catalog, I think, for adaptive devices. You could order those. You wouldn't get them at the corner hardware store.

Cowan: Did you ever see anybody put something together and invent a gadget or figure out some way to do something that they couldn't go buy?

Perotti: Not really. I remember that Don Lorence had a claw--because he couldn't reach. He was not a spinal cord injury. He had some other kind of congenital disability. He was unable to reach, but I think he had use of his fingers. He had this claw--like an extension to his arm--and he'd leave it on his desk, and he'd pick it up and squeeze it and pick up papers and find things with that. But I don't remember anybody actually inventing. Except for Ralf Hotchkiss. He did all these things. He was the inventor [laughing].

Cowan: Who is he?

Perotti: He received a MacArthur Grant.

Cowan: For inventing?

Perotti: Wheelchairs and adapting them. He's a real inventor. He's disabled himself. He had polio.

Cowan: How about cooking? How was that done?

Perotti: Usually, that was the next thing. The things that they would have to modify would be the door, to get in and out; and sometimes once they were in the apartment itself, they might have to take the door off to, say, the bathroom because bathroom doors tend to be a little narrower, so sometimes they'd take the door off to get in and out of the bathroom. They would use the bathroom to empty their bladder bags. The original group of disabled people who moved out of Cowell Hospital, many of them had bladder bags. So that would be one of the modifications.

Sometimes they'd put little strips of durable clear plastic across certain areas of their walls. Say, from three feet down, if there was an area that would get hit a lot by the wheelchair, to keep it from getting damaged, they'd put a plastic strip up. That wasn't to make it accessible; that was just to protect from the wheelchair.

But in the kitchen, a lot of times they had other kinds of adaptive devices on the drawers, to pull them out more easily. The refrigerator, things like that--to open and close. I remember helping people move into apartments, and you'd have to put everything like you would for a very short person. All the dishes and plates and things--if that person was going to use their kitchen, rather than have an attendant do all the cooking, they'd have to have everything on the lower shelves. Everything had to be within reach of somebody sitting in a wheelchair.

Cowan: And people cooked?

Perotti: People cooked, yes. It depended. John Hessler and Herb Willsmore hired me to cook for them. I mean, they just didn't want to deal with it. At that point, John had a full-time job, and John loved to cook--I mean, loved to eat. And he didn't want to deal with cooking. It just wasn't his interest to begin with, and then, of course, being limited in reaching and everything else. So I cooked for them for about a year or so. And a lot of people. There were other attendants who cooked for people. But then there were those people who did cook for themselves. Again, they'd have to have everything within reach.

Sometimes when an attendant would come in the morning to help a person get up, the person might ask them to do certain things, like, "Oh, by the way, I can't reach the freezer. Could you take some steaks out for me and put them on the counter so they can defrost." And "Could you get--" They'd kind of get things set up. I think if you're disabled and trying to really go to school or keep a job or whatever, you have to be just a little bit more organized and plan ahead so that you don't get yourself into a situation where you can't do what you want to do that day.

Cowan: Well, they must have liked your cooking, for a whole year.

Perotti: Oh, yes.

Cowan: Did you stay and eat with them?

Perotti: Yes. At the time I cooked for them I didn't live in Berkeley. I lived outside of town. I lived in Antioch. I just used to come into Berkeley a few days of the week. I worked part-time in the Disabled Students' Program. And during those days that I came in and worked in Berkeley, I stayed in Berkeley in John and Herb's apartment. That was the trade. While I stayed there, I cooked for them. They'd give me money to buy food and we'd plan a menu, and I'd cook, and then I'd eat with them.

Cowan: And whoever came around.

Perotti: Yes.

PDSP Gets Organized

Cowan: Were there some political things going on over their dinner table?

Perotti: Well, that was 1970, so things were still fairly political. The Vietnam War was still going on. And by that point, I really wasn't interested in politics at all. I had gone through the Cowell Hospital movement where people got organized and found their own strength and actually made their demands in such a way that the university responded to them and actually established a program just to serve the physically disabled. That was very interesting. And I worked at the Disabled Students' Program office.

Cowan: This was at John's apartment, the Disabled Students' Program?

Perotti: I think this is the part I'm a little fuzzy on. I think initially they might have started there to begin with, but then they did end up on Durant, right up above the Top Dog [restaurant]. That was pretty early; by '70 they had that office there.

Cowan: I think you said four people started it

Perotti: Well, I remember John Hessler was the director. Zona Roberts was hired as a counselor because she had graduated that very year from UC. She had the credentials to counsel, so she was hired as a counselor. And then Chuck was hired as a wheelchair mechanic, and then they had a secretary.

Cowan: Who was the secretary?

Perotti: I can't remember. I know I became the secretary part time for a while, but I just don't remember.

Cowan: So that was your role there, secretary?

Perotti: I was like a secretary, yes, administrative assistant or whatever they called it. By that time, being an attendant qualified as conscientious objector work, so we had a lot of guys come through there who were conscientious objectors who were referred to that office to get jobs. That's how I met Walter Gorman, in fact.

Cowan: Who was Walter Gorman?

Perotti: He was an attendant for many years. He came to that office, I remember, and I interviewed him because Zona was gone on vacation. By that point, by the time the Disabled Students' Program was set up, things were more formal. People were referred to that office for work, and then they would be interviewed. Zona would interview them and try to get a sense of whether they were qualified and get a little background. Because

now we've got people living in apartments, private apartments, a more isolated, less protected situation than at Cowell.

Cowan: So an attendant referral service began to develop.

Perotti: Exactly. Zona provided counseling services to the new students as they came in. But, actually she was also a referral source. She kept what we would now call a data bank on people coming in and looking for work, and she knew all the people who were looking for attendants.

Cowan: But there wasn't a formal attendant referral.

Perotti: That was part of the services. That's why the office was set up. One of the purposes was to provide attendant referral services, wheelchair repair service, help in finding living accommodations for students, and, once these places were found, help in making them wheelchair accessible and usable by the individual. And also peer counseling services. That was the other thing. People were coming--they were often young--and some of them maybe still recently traumatized because they had had an injury or whatever. So they were often coming there to live for the first time in an independent way, as a disabled person. So Zona would spend a lot of time with them, just offering help, resource help, and providing counseling services.

Cowan: When you say peer counseling, what do you mean?

Perotti: Well, I shouldn't have used that because at that time, the emphasis was not peer counseling. Peer counseling really became one of the cornerstones of the Center for Independent Living, not at the Disabled Students' Program. The Disabled Students' Program was one more office set up by the university to provide services to their students. This office happened to provide services to their disabled students. And part of that was counseling. But the notion of peer counseling, that was one of the cornerstones for the Center for Independent Living and the independent living movement--that counseling would be provided by a peer. In this case, since we're talking about providing counseling services to disabled persons, the counseling would be provided by somebody who was also disabled.

Cowan: John was the director of this program?

Perotti: Yes. It was regular, full-time job. He ran the program, made sure that the program kept within its budget. You know, any basic administrative work that you would have at a university or any other bureaucracy. He went to meetings that were called by the dean's office--their office was under them. And just made

sure that things ran smoothly. John was the executive director. He was probably involved in recruiting students, probably also involved--I'm going to guess--in interviewing prospective students if they came to be interviewed to see if they were a match or not. You know, different things like that. There were a lot of different kinds of tasks.

Cowan: And your role was secretary? Were you still an attendant for Cathy?

Perotti: By that time, I was not an attendant anymore, no. By that time, this was my primary job. It was a half-time job. I was an employee of the university at the PDSP office.

IV CENTER FOR INDEPENDENT LIVING TAKES SHAPE

The Need to Serve Non-Students

Cowan: Did the PDSP program evolve into the Center for Independent Living? Is that a whole separate idea?

Perotti: That's what I started to say. You asked about the evening political conversations. By that point, the students had gotten what they needed in terms of these services, so they could really be more organized in finding attendants. They weren't restricted to being students and living at Cowell Hospital. Up until that time, really the only option was if you were severely disabled--i.e., in a wheelchair--and you came to be a student at Berkeley, you pretty much had to live at the university there, at Cowell Hospital. Now, with the Disabled Students' Program, options were provided. Housing could be found, and now you had choices. You could live at the hospital and maybe move out to your own housing, or start out in your own housing, or whatever.

What started happening is that more and more people who were not students started calling the Disabled Students' Program, asking for these same services. As Berkeley became known to be a place where disabled people--forget even students--but just disabled people were accepted, more and more disabled people were coming to Berkeley. They had been hearing, you know--one by one, one or two here, one or two there--about this program that was accepting disabled students.

Now, all of a sudden, you've got a disabled population, a small one, but you have one, in a city that's very tolerant of all kinds of people. So disabled people were not really considered much of an oddity and could live comfortably--socially and culturally--in Berkeley, and this started to be known around the country. More and more disabled people were coming to Berkeley and the immediate area to live, because of hearing that there was a disabled community building up.

As a result--I know when I worked at the Disabled Students' Program, a lot of non-students called, looking for services. You might say--sure, if it's a slow day and they're looking for an attendant and you happen to know a couple of people, yes, you're not going to just hang up on them. But they certainly couldn't get wheelchair repair service or something like that. Technically only students were qualified to get services from the DSP.

Cowan: So who had the idea?

Perotti: That's what these evening political conversations--a lot of that --was about. It was about, Well, we've come this far. And they would sit around and scheme. John Hessler, Herb Willsmore, Ed Roberts, Larry Langdon--by this time, Jim Donald was gone--Phil Draper--they'd all sit around scheming. What next? What can we do next? By this time, to me, it was just more political stuff. I just wanted to see the war end and kind of go to normalcy in that area. But they were really into, what next for the disabled movement.

Well, what next was widening the scope of the services, providing services to people outside of the student community. And the demands were growing and growing and growing. I think what happened was that they must have written another proposal showing a need to how the money would be spent. I believe they [UC Berkeley] gave them, like, a \$10,000 grant to set something up.

Cowan: So these were the core people who thought of CIL: John Hessler, Ed Roberts--

Perotti: Yes.

Cowan: And they would talk about it.

Perotti: Yes. Oh, incessantly. Oh, yes. This was a big topic. We want to expand this. Well, Ed, I believe, was always a political person. He was a graduate student in political science, so that's what he thought about. That's why he did not go on to be head of the program there. He was in graduate school, whereas John had graduated and was finished with his formal studies. But there were a number of them--they would sit around and they talk a lot about, What can we do next? They wanted changes. Looking back, I wonder if at that time, 1970-71, we realized that this was really the grass roots beginning at the civil rights movement for people with physical disabilities.

I mean, they had really gotten a feel, a real sense of what power they had. First there was nothing, then there was Ed at Cowell Hospital, and then there's John, and now we're growing geometrically. There's more and more people. Now there's eight people up there. Now there are women. And there's a whole slew of attendants and all this kind of stuff. And then--BAM!-- there's a Disabled Students' Program. All set up by the university, with its own stationery [chuckling].

Cowan: Do you remember when they set up CIL? Were you working for them?

Perotti: I did my usual thing. I worked and saved my little pennies, didn't waste anything on cameras [chuckling] or anything like that, and I left the country for almost a year. When I came back, they had the money. They had that first grant. That was around 1971-1972.

Cowan: They had the money, or they already had a place?

Perotti: They were running it out of John's apartment, I'm pretty sure.

Cowan: CIL. The Disabled Students' Program had been run out of his apartment, but it moved to Durant?

Perotti: Right.

Cowan: And now CIL was being run out of his apartment, and they were looking--

Perotti: Yes, and they were looking for space. I was in South America for about a year. I came back, and I saw they had gotten this money, and they were talking about setting up an office in Berkeley. I left Berkeley again, and I went to Santa Cruz, and I worked down there for about a year and a half, at UC.

CIL Moves to University Avenue

Perotti: In the meantime, they set up an office on University Avenue. I was still in touch with John Hessler and Ed and a number of other people. I was very close friends with the Roberts family. I remember at one point about 1973 I was visiting Ed, and I said, "Gee, I have a pretty cushy job, but it's so boring. What's going on up here?" He said, "Hey! We just got this grant for a pilot program for independent living, peer counseling. You interested?" I said, "Yeah, yeah, I'm interested." He said, "Great. Because Don Galloway, who's already been hired as

director of the new program, will be down in Santa Cruz area a week from such-and-such. If you want to talk to him--"

And for me, that's what happened. I was still working at UC Santa Cruz, and I met with Don Galloway, who was blind and black. Big, tall, he cut quite an impression when you met him. He was always dressed very elegantly and very modern. I don't mean elegant in suits, he had a lot of style. He was a very impressive person. He came to Santa Cruz area and we met. He interviewed me for the job. I had all the credentials for it. I mean, I had worked a lot with disabled people, and I knew a lot of people who were involved at the program. So I was hired to be the administrative assistant. So I gave my two weeks' notice at Santa Cruz. I packed up, and came back to Berkeley. Always back to Berkeley [laughing].

Cowan: Was John the director?

Perotti: No, Ed was the director of CIL. John stayed as the director at UC Berkeley, at the Disabled Students' Program, for a number of years. Ed became the director of the Center; he was the first director of the Center for Independent Living. He kept that job for I don't know how many years, maybe--I'm going to guess four or five years--until Jerry Brown was elected governor, and then Jerry Brown appointed Ed to be the director of the Department of Rehabilitation. So that was the big--

Cowan: That was the big coup.

Perotti: Yes. He left CIL.

Cowan: What was Ed like as director, as opposed to what John was like?

Perotti: They were the best of friends, and they were truly peers. Ed would say of John Hessler, he was one of the few people who would really argue with him and back him down on issues. He was one of the few people who could actually stand up to him. Ed was a lot more charismatic than John. John was fairly conservative in his nature. They're both very, very intelligent people, very intelligent. But very different in their approach. John was much more conservative in the way he dealt with people, too. Ed was just a more relaxed kind of person and very warm, and very open. He didn't care who you were or where you came from. He treated people fairly much the same.

Four Cornerstones of CIL

Cowan: Did the center begin to expand quite quickly?

Perotti: Oh, yes. It was outrageous. They opened the center--I wasn't around when it first opened, but it was based on the same concepts that the Disabled Students' Program was based on.

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Perotti: Basically, there were four cornerstones. That just came off the top of my head. The attendant referral services; wheelchair repair; help in finding housing; and peer counseling. Now, at this point, at CIL it became peer counseling. That was to say that disabled people would provide counseling. One of the criticisms that was made of CIL and--I don't know; it's probably valid--is that coincidentally, it just so happened that the people who were involved in this program during the early years were quadriplegic. Most of them had become disabled through spinal cord injury. In the case of Ed, it was through a severe case of polio that nearly killed him. In the case of John, it was through an accident, where he broke his neck. Many of the people--most of the young men and women--were also quadriplegics involved in some kind of spinal cord injury. And so that was their orientation.

Some people felt maybe that blind services didn't get its just dues; there was no deaf component in the beginning. But, you know, it started from nothing and it grew. And it did grow to include a blind services and a deaf component. But it was definitely, in the early days, dominated by quads with spinal cord injuries.

Cowan: How many employees were there, do you think, when they were still on University?

Perotti: Before they moved to Telegraph? I don't know. It kept growing and growing. In the beginning it started off with just a handful. You could never tell because there were hangers-on, there were volunteers. In the beginning it was mostly people who were interested, and you had to be kind of aware that this was even happening. It was just a small, itty-bitty blip on the whole consciousness-raising movement. So you had to really know somebody who was involved to be around.

But then, as it grew and started getting a little media attention, more and more people were going to check it out and find out what was going on. But I would say, when CIL first

opened up, I don't think there could have been more than a half a dozen people. But it started growing pretty fast as they got more and more grants. They were applying for grants.

See, they could get away with having a lot of people there because a lot of people were on disability, you know, some kind of SSI [Supplemental Security Income] funding or whatever. They could afford to live on that money, but if they'd gotten a regular, full-time job at a community agency, maybe at that time it would have paid \$7,000 or \$8,000 a year. Well, a disabled person would be hard-pressed to live on \$7,000 or \$8,000 a year because they have to pay attendants, they have special medical needs in terms of wheelchairs and things like that. So a lot of them would just strictly do volunteer work and keep their benefits because if they didn't do it that way, they couldn't afford to have the job.

So it grew very fast. As people could see that this was really having an impact, more and more people were attracted. I'm sure that by the time they moved to Telegraph Avenue, there must have been at least forty or fifty people working there.

Cowan: Between volunteers and paid people?

Perotti: Maybe. Maybe even more than that. It's hard to know.

Cowan: What kept it all together?

Perotti: Well, people's commitment, first of all, number one. Number two, the fact that it was successful. That was giving it the impetus to keep it moving. And number three, a lot of people who were involved had nothing to lose. Things had to get better. They couldn't get worse. It was great having a Disabled Students' Program, but that only served a limited sector of the society, of the disabled society, and most disabled people at that point were not living independently. The ones who were in Berkeley were pretty much the minority. They knew that, and they knew they wanted to see change.

Grant for the Research and Demonstration Project

Cowan: As the program expanded, services developed. A recreation program had begun--

Perotti: Right.

Cowan: --and a disabled women's group.

Perotti: Those came a little later, yes. There were a lot of spin-off groups. When they moved over to Telegraph Avenue, they already had the blind services. I think they moved to Telegraph Avenue around '75. I was there when they moved. I had a full-time job with the group. It was a special grant. It was the biggest grant they'd gotten, \$100,000 a year for three years. Funded by the Department of Health, Education and Welfare. It was for The Research and Demonstration (peer counseling) Project. That grant alone hired about a dozen people. There were six projects in the country that were funded, and each project had a different model, and our project, the one that I was hired to work on, was based on peer counseling. That was the basis of it, that the services would provide counseling services to other disabled people, and the counseling services would be provided by disabled people who were successfully living independently.

So they would be the role model; they'd have the basic nuts and bolts on how to do this; and they would also have access to information. They'd have attendant referral pools at their disposal; they'd have a lot of information and resources. That was one of my main jobs, was to try to keep a lot of information, a repository of a lot of information. I was not hired as a counselor, obviously, because I'm not disabled.

When we moved to Telegraph Ave, they already had the blind services. I remember that. The wheelchair repair, that was easy to get funding for, and that was growing by leaps and bounds. They had a whole garage on Telegraph Avenue, an entire garage set up for wheelchair repair. And, you see, part of that, too, is that then they brought people in to train them on how to do wheelchair repair.

There was a lot more grant money back in the seventies, too. There was an interest in this because--it was a dual purpose: certain groups providing services and at the same time training people to provide services. BORP [Bay Area Outreach and Recreation Program] came a little later.

One of the big programs that got set up fairly early was a huge success and is still operational, but it's completely independent of CIL, is the computer training program. It's still running today. It's been running for over twenty years.

Cowan: Was there always adequate funding? Did it pay everybody's salary?

Perotti: Yes, but barely. We all had meager salaries. I mean, I did great on my salary because I was so frugal back in those days [laughing]. I bought a house. But if I had my spending habits today, I would have been hard-pressed to live on that kind of money. I put in long hours. My first year in helping to get that program set up, I put in about fifty hours a week every week. I worked long hours. It was a life style. It really was. I felt like I was doing something valuable.

CIL Expands Services and Personnel

Cowan: Did they manage the money well? And was Ed still the director?

Perotti: That's one of his negative traits. Ed could never even keep his checkbook balanced. He was still the director, so that really wasn't his responsibility. Initially they hired somebody who--all he knew how to do was balance his checkbook. He had no real bookkeeping experience. I mean, who's going to go work for a place like that? There's no money. What accountant is going to take a part-time job for low wages? Everybody's jobs were percentage. "Oh, there's a one-eighth job opportunity," you know? And sure, for a student, that's great. That's all you need. You don't want a full-time job, so you go over there. You stop in two hours a day on your way home from class, and you do this or that or whatever.

But you couldn't get professionals. So they never had a professional bookkeeper until they really had expanded their budget to where it was a \$1 million-a-year budget. Then they hired a controller, and, my God, that guy spent hours and hours and hours and hours trying to straighten the books out. Because they started with practically nothing, and they had a bookkeeper who was just that, a bookkeeper. He tried and he did what he could, and things grew so fast. So they didn't manage their money very well.

They were always in debt because they were always trying to grow. I mean, they did good things. They always were trying to grow, so maybe "x" amount of money would come in for Project A. Well, they would take half of that and give it to Project A and take the other half--because they had this other brilliant idea of another project to start! Robbing Peter to pay Paul. I mean, they were always sitting around brainstorming as to what they could do next. You know, more services and more--

They had vans by this time. They had a whole fleet of vans that were going all over the place, giving people rides. Then they had to repair them. So that was another grant. Oh, well, let's repair them! We'll teach people how to repair them! It went on like that.

Cowan: When you said they always sat around brainstorming, who do you mean by "they"?

Perotti: The ones I remember were Ed, John Hessler. By this time, Judy Heumann was involved. She's a real political animal. She has some kind of an appointed job now [Assistant Secretary of Education], some appointment from Clinton.

Cowan: In Washington.

Perotti: Phil Draper, who became the next executive director of CIL. Who else was involved in those days? Oh, people like Eric Dibner, a non-disabled person. Debby Kaplan. She's around. Hale Zukas. They'd sit around and have meetings. They lived and breathed this stuff.

Cowan: At the time, do you remember how you felt, what you were thinking? Were you thinking, Gosh, these guys are changing the world?

Perotti: No, I didn't really think that. I didn't see the impact of it all because when you're just living it--I mean, looking back, you go Wow, so much happened so fast, but when you're living it, it's not that fast. It's a little here, it's a little there. For me, you know, I really felt I had to start settling down. I was in my early thirties, and really, it was a way for me to have a full-time job without working in some boring corporate environment. That was the attraction. I was attracted by the fact that there were a lot of really bright, quick-thinking people who weren't boring, who were very interesting. People there--like any sub-culture in Berkeley, people have traveled all over the world, they have areas of expertise, knowledge, interesting people. That was the draw for me.

I never was interested in the political aspects of it. It was just a byproduct as far as I was concerned. I even used to laugh at the guys. See, "the guys." It just happened to be that way. There were some women who were involved, like Judy Heumann and Joan Leon. They were as big a player as anybody. But I just would kind of laugh and scoff, "Eh, they're doin' their thing." I'd rather go to the movies or something.

Cowan: What about the Disabled Women's Project? That sounds interesting. What was that?

Perotti: I don't think I was around. No, I think that must have come later. I remember when BORP started. BORP was the Bay Area Outreach and Recreation Program. It's a recreational program. That was another service that they wanted to do, now that they had the basics taken care of in terms of housing and helping people to find attendants and keeping their wheelchairs fixed and everything, expanding to recreational services.

Discrimination and Civil Rights Issues

Cowan: And computer training.

Perotti: Yes, computer training. But also during this time, as CIL was growing, so was the whole political movement to make some changes. Things were still happening to people where they'd make an airplane reservation to fly home to see their parents in New York or something or just to fly to L.A., whatever. They'd get to the airport and they wouldn't be allowed to board the plane. "You're in a wheelchair. We can't board you." These things were happening.

And I remember, too, people were turned away for housing because they were in a wheelchair. Sometimes they'd show up--even in Berkeley. And they'd say, "Oh, we don't have any housing."

Cowan: Discrimination.

Perotti: Yes, discrimination. I think a lot of people just were afraid, were afraid of disabled people--on airplanes--because of liability reasons. And so that was a big thing that was going on. On one hand, there was this, oh, let's have more services. But on the other hand, it was, hey, did you hear about so-and-so got turned away at the airport? Or, did you hear about so-and-so, got turned away.

Cowan: The civil rights part of it.

Perotti: The civil rights began to develop big time. I think it was in 1977 when they had the 504 sit-in over in San Francisco. I was working at CIL then. I went to work at CIL every day, which was pretty much a graveyard at that point [chuckling]! There were very few people around. They were all in the city at the Federal

Building. But, they'd call and say, "There's more people over here. Can you bring some blankets" Or "Can you go to so-and-so's house and get some clean clothes?" Or "We need some food." Stuff like that.

Cowan: So you actually went over and dropped in.

Perotti: Yes, dropped in and brought things. I can't remember. I guess they let me in. I don't know. But I know things were delivered to them. Medication, fresh clothes, things like that.

Cowan: Was that pivotal, that it began to shift from services to civil rights?

Perotti: Yes, I think so, yes. And that, again, once the Disabled Students' Program really made everybody feel their muscle, they realized what they could do. And then, once they had this other program, CIL, it was like the churches in the black communities. It was a place for people to come together. It's hard to have a movement if there's only two people around who are involved. So it was really a focal point, and more people came in.

Our project, the Peer Counseling Project, was funded for three years initially. Actually, I think it went on for four, four and a half years. And by the end of the third year, of the six models it was the only one still in place. I mean, not only was it a success. It was the only one that was still going. It was a huge success. And that model, the model that we set up within CIL--we were like a little CIL within CIL--we had to document everything. The data was being sent to the Urban Institute. They were supposed to be doing all this analysis and stuff.

We were considered a big, raging success, even before the project was over and the analysis was completed. Other cities were calling CIL for consultations, to model programs, to get information to help to model programs after CIL in their own cities. So that was another thing, too. This thing was really growing. Not only was it providing services all over the place and new programs and trying to--the civil rights fight--but also training, consulting, and providing information to other cities across the country for the same thing.

One of the big things that I remember, Eric Dibner did the first ramp. We used to have these guerrilla rampings. He'd go out in the middle of the night with his little bag of cement, chip away at the curbs and make a little ramp.

Cowan: On the city streets?

Perotti: Yes, on the city streets. They're all ramped now. But this was in 1968.

Cowan: He'd actually chip away the cement.

Perotti: Yes [laughing], and make a little ramp. Some of his old ramps were around for a while. That was another thing, fighting to get all the curbs set up and things like that.

Thoughts on Why the Independent Living Movement Happened

Cowan: Why do you think all of this worked so well at this time?

Perotti: I think a lot of it had to do with the time.

Cowan: That was important.

Perotti: The time, and the technology. I don't know how others would feel about this, but I think having a power wheelchair is really something. It's really a big breakthrough. You can actually get out on your own, as opposed to having somebody help you get dressed, and having them lift you into your chair, and then having them push you wherever you want to go. Especially quads. People like Susan Sygall, if I remember correctly, she could do a lot in a wheelchair. She had upper-body strength. But most of these quads don't have that upper-body strength, and they can get around in a push chair in their house. You know, maybe from the kitchen to that room and there. But not much beyond. Certainly not in a city like Berkeley, where you have hills. I think that the technology was there.

Cowan: So that was key.

Perotti: That was key because there was the independence of getting around. And it was the end of the sixties. It was the beginning of the seventies. People had organized. Stopped the Vietnam War. That succeeded. It really was showing people. There had been the Civil Rights Movement in the sixties for black people, and I think this was just a natural outgrowth of all of that.

I remember one woman, Jane Jackson. She was a black woman, disabled woman. She said, "You know, I have had to fight for my rights twice. Once in the sixties as a black person. And now in the seventies as a disabled person. How many people have to fight for their rights twice?" [laughing]

The Role of Non-Disabled Persons and Discrimination Issues at CIL

Cowan: What was the role of non-disabled people at CIL? You were a non-disabled person.

Perotti: Yes, well, like I said, when I was interviewed and hired, it was as an administrative person. I guess you could say there was a certain amount of discrimination, in a way, toward non-disabled people. I didn't really feel it because initially I wasn't that interested. I mean, I wasn't doing this for the politics. I did it because it was a job, and I wanted the money, and I liked the people I worked with. I really, really liked them. They were interesting and stimulating people.

But, really, there was a certain point where the disabled people were trying so hard to prove that they didn't need non-disabled people that sometimes you would be pushed into the background. I remember one time one of the peer counselors on my project had an appointment with somebody to provide counseling services, and that person in a wheelchair came to see her, and there was no room near her desk because there was a chair sitting there, and neither of them could move the chair. The counselor said to me, "Linda, could you move this chair for me?" I said, "Sure, no problem." I got up and moved it. And she said to the other person, "See, once in a while we do need non-disabled people." [laughing] I wasn't thrilled with that comment.

Again, I stayed there for three and a half years, and I knew I had reached my ceiling, my limits as a non-disabled person. I wasn't going to really have much interesting work to do there after that.

Cowan: No place to go.

Perotti: No place to go. And that was fine. I never chose it as a career, and I moved on.

Cowan: How about sexism? In your view, did women not rise to top positions because they were women?

Perotti: I think it was pretty sexist in certain ways, yes. I remember the first women who were attracted to the program. They were like me. They weren't that interested in that kind of political maneuvering. So, of course, if you're not interested in it, you're not going to rise to the top. I thought that there was an imbalance in the pay structure. I remember complaining about that. The non-disabled women always ended up being secretaries or administrative assistants if they wanted to make us feel good.

But, yes, CIL had the same problems as the rest of the world did. I don't remember very many Latinos there. All of the students who came initially were white. Most of them initially were men, and then there were some women who came. It was the same old thing, pretty much. But I guess that's the way life is. They still achieved a lot of greatness.

I remember when Ron Washington came. He was probably the most political. He was a black person in a wheelchair, quadriplegic. He was very politically oriented. And Don Galloway, who was head of the Peer Counseling Project. He was black. That was a big coup for CIL, to have a black person as the head of a project. It was kind of a white thing to begin with, and that's what it attracted, other white people.

Cowan: But that changed over time?

Perotti: Oh, yes. Over time, it changed, yes, it did. By the time I got there in the mid-seventies, there were two black people on our project. We had about ten people on the project.

More on CIL Leadership

Cowan: Was CIL a kind of launching pad? Did people go off from CIL into big, important jobs somewhere else?

Perotti: A lot of people did.

Cowan: Did it happen a lot?

Perotti: Yes.

Cowan: Ed.

Perotti: Well, Ed went to become the director [of the Department of Rehabilitation]. And when he went up to Sacramento, he talked John Hessler into leaving the Disabled Students' Program, and John took a pretty good job with Ed in the same department. John did a smart thing. Before the four years were over with, he ended up transferring to another department within the government in Sacramento, so that when the four years ended and Jerry Brown was not reelected and Ed lost his job [chuckling], John still had a job! I tell you, he's very clever, very clever, yes.

Yes, a lot of people did. Look at Judy Heumann. And who was it that started that computer training program? Scott

Luebking? He ended up with a very nice job over at SyBase. For a number of years. And his partner Neil Jacobson. He ended up with a nice job. A lot of people did, some people didn't. You know, some people didn't. Of course, there were some people there who had degenerative disabilities, like multiple sclerosis, who died and others who maybe never could have a job, or didn't want to. But a lot of people did get fruitful employment. Herb Willsmore sells real estate up in Sonoma now, Santa Rosa.

Cowan: Did you notice a significant change when Jerry Brown's administration shifted? Did funding or support from the state--

Perotti: I think by that time that bill--what was it? 504?

Cowan: Yes.

Perotti: That bill had passed, and things were now law. Ed really made a shift in the Department of Rehabilitation toward providing services for the severely disabled. They felt that a lot of money was being used up by people, say, who had minor problems, whereas people who had more serious problems were considered non-rehabilitative and weren't getting attention. So money shifted in that sense.

Cowan: Ed was the cause of that.

Perotti: Yes, when he was in the Department. That was always their big beef with DR, that you had to really fight. If you had a severe disability, they didn't really want to provide a lot of services because you weren't rehabilitative, and it was just a lot better to just go stay in a convalescent home. Which was very expensive, actually. But that's what happened to a lot of people.

But once I finished with the R&D program at CIL, I really wasn't involved anymore with the disabled movement. I stayed friends with a lot of people who are involved. I remained close with the Roberts family. But I made a severe career change [chuckling] and started a gardening business.

Cowan: After you left CIL, you just didn't stay really in touch with the community?

Perotti: No, not much. I still lived in Berkeley, so of course I continued seeing people from the disabled community, but more in a social context, not political.

Final Reflections

Cowan: Well, is there anything you'd like to finish up with in terms of CIL or the Disabled Students' Program or anything you want to look back or reflect on?

Perotti: To me, it was a very important part of my growth. I never chose being involved with the disabled movement as something that I wanted to do. I just happened to be friends with people who were involved in it. And I feel very lucky that I was because I look back at the three and a half years I worked at CIL, and I'm very proud of the work that I did there.

The pay was very low; the hours were long; it was certainly not glamorous work. Our office was in the middle of the building. We did not have a window. We worked in a cinderblock room--it had been the parts department when the building housed an auto repair place. But, you know, I was very proud of the work that I did. People at the time, when I worked there, other non-disabled people who didn't live in Berkeley, said, "How can you work in a place like that?" And I'd say, "What do you mean? It's no big deal. You just go and you work. It's like working anywhere. It's more interesting than most jobs."

And there certainly was a lot of flexibility. It's the first place I had ever worked that had paid mental health days. It used to be you had to really be sick to have a day off? They had mental days off! [laughing] They started mental days off.

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Cowan: Linda, you were just reflecting on your entire experience with the disabled community and at CIL.

Perotti: Yes. I think one of the reasons I left the R&D project before it had completely ended--was because it was already deemed a success, and we had accomplished a lot during those years. I had seen so many changes in the legal structure and people's attitudes, and I felt like I had reached the limit in terms of what I could do as a non-disabled person, that there was not much growth there for me.

And also I was burnt out. I had heard a lot of horror stories. I mean, with our clients. Our project was set up to deal with severely disabled people, so we provided services to people with multiple disabilities. Over the three and a half years, you know, I met and heard a lot of really tragic stories.

I just wanted--I wanted, I guess, a different point of view on life [chuckling]. I had had enough of that.

And I did spend a lot of time indoors. It was an indoor job, and I was in that little room without windows for three and a half years. I really felt the need for a change. I didn't know what I was going to do, but I ended up starting a gardening business, which was at the opposite end of the spectrum. But I did still keep in touch with people because I stayed in Berkeley and could see that things were still going on. And I felt so proud. I remember when Michael Pachovas, a huge guy, another quad in a wheelchair, went to fight to keep--I think it was the American River from being dammed. He went and chained himself to a gate by the river there! And I saw him on television! I was so proud! These are my friends! I still felt peripherally involved because I knew so many people who were still very, very involved, and I was very proud. I still am very proud of the work that I did during that time.

Cowan: When you look at what it's like today, do you think there was a lot of discrimination then and that has changed? There's less discrimination against disabled people now?

Perotti: I think in a lot of ways things have changed for all people--for disabled people, for all minorities who were oppressed or just not given the same rights as others. I think there were a lot of changes. But in a lot of ways, there's still a lot more room for growth, especially, I think, in individual attitudes. Laws have changed, buildings are accessible, but, shoot, I work in a building with about eight or nine thousand people. I think I've seen two people--two employees there--in a wheelchair in the eight months that I've been there. A perfect job. I mean, I have the perfect job for a person in a wheelchair, with the kind of work I do. But I see very, very few disabled people around. I don't know. Maybe the telephone company just doesn't attract disabled people--I know that they're conscious of being equal opportunity employers in every way. But I don't see them yet.

Cowan: How about in the community you live in now? Do you feel that buildings are accessible, that there are ramps?

Perotti: Oh, yes. Well, they have to be. It's the law.

Cowan: But you don't see disabled people working behind the counter very much.

Perotti: No. I don't see that abundance of disabled people around, in a place like Castro Valley. You see in Berkeley more and more all over the place. Maybe Castro Valley, being hilly and not having

good public transportation and being a little spread out, maybe it's not a good community for disabled people.

But, you know, I think great advances have been made. Certainly, even just in marketing. There are so many companies now to get wheelchairs from, and they're streamlined and really neat looking. So there are some great changes that have happened.

Cowan: Do you stop and think that you had a role in this change?

Perotti: Well, you know, it's funny. I think the thing that strikes me the most is the logo that's used by the disabled people. A lot of times, when I see one, I'll be someplace else, like at an airport in another city. And it will make me feel proud. I'll say, yeah. That logo kind of sums up, to me, the achievements of the disabled movement because you see it all over the place. You see it internationally. And often when you see it, it will mean there's a wheelchair-accessible bathroom or whatever, something like that. But to me, it means more than that. And whenever I see that, I always feel proud.

Cowan: Do you have any final things you want to say? How about how this affected your life?

Perotti: Well, I think during that time I really worked--took jobs in situations that were interesting and not because of the money that was involved. And I think, if anything, I would really advise young people today to really do things that they feel are worthwhile, even though there's not a lot of money involved, because I think later on it will really make them feel better about themselves.

Cowan: All right. Well, I think we're finished.

Perotti: Thank you.

Cowan: Thank you.

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SHARON BONNEY

Interviewer/Editor

Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

Sharon Bonney received a B.S. in Communication and Journalism from the University of Illinois and an M.A. in Public Affairs from the University of Iowa. After working as a reporter and freelance writer, she established the Services for Handicapped Students Office at Iowa before working in the Department of Rehabilitation as a client advocate in Tennessee.

In 1979, Ms. Bonney became director of the Physically Disabled Students' Program at UC Berkeley for nine years. She later was the assistant director for the World Institute on Disability. For the past two years, she has been an interviewer/editor for the Regional Oral History Office at UC Berkeley for the Disabled Persons' Independence Movement Project.

Her professional activities include numerous publications on disability issues; founding member, president, treasurer, and conference chair of the Association on Handicapped Student Service Programs in Post Secondary Education (now known as AHEAD); participant in the White House Conference on Handicapped Individuals; and current member of the Society for Disability Studies.

Ms. Bonney has muscular dystrophy and is a wheelchair user.

KATHRYN COWAN

Interviewer/Editor

Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

B.A. in Communications from California State University Hayward.

In the 1980s, she was a job developer for a disadvantaged youth organization. She developed a program that brought youth together with senior citizens who served as mentors by sharing their personal and work histories.

She has a long-standing interest in political and social change, and followed closely the civil rights, anti-war and women's movements. In the early 1990s she became interested in the disabled persons' independence movement. In 1995 she was diagnosed with muscular sclerosis.

She is currently the librarian for HomeBase, the Center for Common Concerns, a public interest law firm that develops and supports policies and programs to reduce and eliminate homelessness.

In 1997 she joined the staff of the Regional Oral History Office, The Bancroft Library, University of California, Berkeley, as an interviewer and editor for the Disability Rights and Independent Living Movement oral history series.

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